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PARENTS' PERCEIVED NEEDS OF PRESCHOOL-AGED SIBLINGS OF CHILDREN WITH DISABILITIES

BY

DARLENE MARCELLA TANCHAK

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILMENT OF THE REQUIREMENTS OF THE DEGREE OF MASTER OF EDUCATION

IN

SPECIAL EDUCATION (SEVERE DISABILITIES)

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

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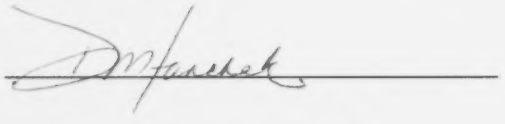

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and research for acceptance, a thesis entitled Parents' Perceived Needs Of Preschoolers Having Siblings With Disabilities submitted by Darlene Marcella Tanchak in partial fulfillment of the requirements for the degree of Master Of Education in Severe Disabilities.

Linda McDonald
Supervisor

Gerry Kysela

Janis Blakey

Date Sept. 16, 1993.

ABSTRACT

The purpose of this study was to investigate parents' perceptions of the unique needs of their preschool-aged children having brothers and sisters with disabilities. Potential influences from both within and outside the family were identified as parents indicated current levels of need for their families in each of the following areas: (a) information, (b) professional support, (c) community/generic support, (d) family support, and (e) strategies. Additional information pertaining to family needs, the current needs of their children with disabilities, and their preschool-aged children without disabilities were identified as indicated by the parents during the Preschool Sibling Survey and follow-up telephone interview. The current research analyzed 17 surveys, and 15 follow-up telephone interview forms, the total available at the time of the analysis.

The results of the study indicated that areas of very high need for the families included: (a) information for accessing specialized therapy services, and future school placements; (b) access to a daycare program or preschool program for their children with disabilities, (c) access to recreational programs for their children with disabilities, (d) more quality time with children with disabilities, and (e) more quality time for themselves. Additional areas of moderate to high levels of need for the families included: (a) strategies on reducing and coping with stress and anxiety, (b) strategies on effective communication skills with family, school, staff, and medical professionals; (c) strategies on how to manage the behavior of their children with and without disabilities, (d) strategies on how to advocate for their children with disabilities, and (e) strategies on how to teach their children with disabilities (e.g., self-care skills).

With respect to their children with disabilities, almost three quarters of the parents (72%) indicated that they usually and always needed to encourage their children in the following areas: (a) to be independent with personal-care and self-help skills, (b) recognize and feel good about the positive things he/she does, and (c) understand expectations for appropriate behavior and consequences for unacceptable behavior. With respect to their children without disabilities, over half of the parents (59%) indicated that they usually and always needed to encourage their children to recognize and feel good about the positive things that they did. One third of the parents (35%) indicated that they always needed to praise their children for the time they spend taking care of their siblings with disabilities.

Comments, concerns, and/or recommendations elicited during the telephone interview were included in the results and discussion sections. The implications of these results and possible measures that could reduce high areas of need were considered.

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have learned that the first duty of love is to listen. The words of George Eliott express how much I value and cherish our friendship:

> Oh the comfort, the inexpressible comfort of feeling safe with a person; having neither to weigh thoughts nor measure words but to pour them all out, just as it is, chaff and grain together, knowing that a faithful hand will take and sift them, keep what is worth keeping, and then, with the breath of kindness blow the rest away.

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CHAPTER 1

Introduction and Statement of the Problem

This study explored parents' perceptions of the needs and concerns of preschool-aged siblings of children with disabilities. The conclusions and implications are based on quantitative and anecdotal data collected by survey and telephone interview with the researcher. The survey requested demographic information, as well as information on current family needs, current needs of siblings of children with disabilities, and current needs of children with disabilities. Fifteen out of 17 respondents who completed surveys participated in a follow-up telephone interview to discuss general needs and concerns of preschoolers having siblings with disabilities in more detail.

Purpose of the Study

This study was designed to investigate parents' perceptions of the needs and concerns of preschoolers having siblings with disabilities. The Sibling Survey developed by Judy Itzkowitz (1989), was designed with the intent of identifying current needs and concerns of adolescent-aged to adult-aged individuals having siblings with disabilities. Information was collected under the following categories: information, professional support, community/generic support, family support, and training (Itzkowitz, 1989). The purpose of the study was to summarize available information in order to improve and/or develop useful resources, programs, and local services for siblings of persons with disabilities (Itzkowitz, 1989).

Questions selected from the Sibling Survey were modified to address the needs of families having preschoolers with and without disabilities. For purposes

of the present study, parents with children in one of three Early Education Programs were asked to complete a three part survey. Parts 1 and 2 of the survey included questions that were developed by the researcher as well as questions revised from the Sibling Survey. Part 3 of the survey included questions designed by the researcher to investigate the unique concerns of preschoolers having siblings with disabilities, and their need for information, understanding, and support.

At the end of the survey, there was a consent form requesting assistance from parents to participate in a follow-up telephone interview to discuss general needs and concerns of preschoolers having siblings with disabilities in more detail. More specifically, the researcher was interested in discussing the positive effects and concerns of children with disabilities on their siblings without disabilities and vice versa, the quantity and quality of interactions between siblings, and attempted strategies for facilitating cooperative interactions between siblings. Additionally, parents were encouraged to provide suggestions and/or recommendations to assist other parents in enhancing the lives of their children with disabilities and their siblings.

In the following sections, the background of the study is presented with a focus on issues of concern for young siblings of children with disabilities, the need for honest and precise information, and interventions for young siblings of children with disabilities. A detailed description of the rationale, research questions, definition of terms, and significance of the study follows.

Background To The Study

> Erika is not quite 3 and is definitely the "older" sibling in our family. She has gone through a unique process in order to deal with Thomas in her own very special way . . . as the months go by, she becomes more of a helper, and she must keep asking me, "Why is Thomas crying?" and I keep saying, "I don't know" . . . together we continue to come up with ways to help Erika deal with her special brother. (Post, 1991, p.16)

Current literature acknowledges the significant impact that a child's disability has on the parents, particularly the mother. It is therefore no surprise that children with disabilities will also have an impact on their siblings. Powell and Ogle (1985) stressed that siblings of all ages have a number of genuine needs and concerns about their siblings with disabilities. Generally speaking, "their concerns focus on the cause of the handicap, the child's feelings and thoughts, prognosis for a cure or improvement, the services the child needs, how they can help the child, where the child lives, and what the future holds for the child" (Powell & Ogle, 1985, p. 45).

Unfortunately, in an attempt to address the needs and concerns of parents, researchers have failed to provide empirically valid evidence supporting the notion that siblings can be negatively affected by their brothers or sisters with disabilities (Lobato, 1983). In fact, as researchers attempt to investigate the effects of children with disabilities on their siblings and the specific needs of these siblings, qualitative data is being collected solely on parental and adult-aged siblings' accounts. Despite growing interest in the impact of children with disabilities on their preschool-aged siblings, most research focuses on programs for teaching preschool-aged siblings how to be effective instructors for modifying their siblings' behavior (Cash & Evans, 1975), and how to teach new skills in each functional domain (Brody & Stoneman, 1990; Brody, Stoneman, Davis, & Crapps, 1991).

Consequently, preschool-aged siblings' need for accurate information, attention, understanding, and support may have been overlooked. It is appropriate and essential for parents, who might be unaware of the needs and concerns of siblings, to have more opportunities for identifying these concerns at an early age before potential problems evolve (Edmundson, 1985; Fischer & Roberts, 1983; Powell & Ogle, 1985; Simeonsson & Bailey, 1986; Turnbull & Turnbull, 1990). As Gayton (1975) noted, service providers need to focus on "anticipatory guidance" for siblings, to assist in minimizing siblings' "unusual problems," and maximize their "unusual opportunities."

Issues of Concern

> You, too, are a valuable, developing individual human being. You, too, need to be recognized, to be loved, and to develop into the best person you can be. Your brother or sister with the handicap needs to experience the most robust, risky, rough-but-kind interactions with you that he or she can tolerate--as close to normal sibling relationships as possible. (Perske, 1981, p. 75)

Siblings of children with disabilities have expressed numerous concerns and questions about their brothers and sisters with disabilities, the future, their families, and themselves. Some siblings may require opportunities for discussing their concerns and fears, while others may need basic information regarding their brothers' or sisters' disabilities.

This section addresses some specific needs and concerns of siblings having brothers and sisters with disabilities. It is the researcher's intent to discuss these needs and to review interventions used to meet their special needs.

Fear. Overidentification may occur when children without disabilities fear they may have disabilities like their siblings. For example, a child having a sibling with a disability may ask, "Am I disabled too?" or "Will I be blind someday?" (Binger, 1973; Trevino, 1979).

Although these concerns may appear to be irrational, they can be very real to young siblings (Biba ce & Walsh, 1980; Burbach & Peterson, 1986; Lobato, 1993; Potter & Roberts, 1984). In fact, in an article discussing childhood leukemia, Townes and Wold (1977) described young children (i.e., from infancy through the age of 7 years) as having to depend on their own interpretations of experiences when trying to understand their siblings' disabilities. It is no surprise, therefore, that young children having siblings with disabilities may develop unwarranted fears regarding causes of their siblings' disabilities. Some preschoolers may blame the parents for not protecting their siblings from harm (Binger, 1973), while other preschoolers may blame themselves for their siblings' disabilities (Perrin & Gerrity, 1981).

Guilt. When one child in the family has a disability, and one child does not, there may be fewer opportunities for a sibling relationship with some elements of "reciprocity" and "complimentarity" (Atkins, 1989; Dunn, 1983;). The sibling bond may be jeopardized as siblings without disabilities struggle to understand how they might be responsible for their siblings' disabilities. A child might wonder why his/her sibling has the disability and not him or herself (Bank & Kahn, 1982; Osman & Blinder, 1982; Seligman, 1983). In addition, Lobato (1993) suggested, "when a young sibling observes parental distress, especially when the ill or disabled child is not immediately present, there is a strong possibility that the preschooler will perceive him or herself as having some role in the parents' distress" (p. 87). Powell and Ogle (1985) stated that young siblings may feel pressure to be an extra good child.

Some siblings recalled memories of their feeling guilty about the time their parents spent with their brothers and/or sisters with disabilities. Other children have expressed guilt feelings as they reflected on situations where they resented

being embarrassed in front of their peers and making excuses for their siblings' behavior, appearance, or use of adaptive equipment (Osman & Blinder, 1982; Powell & Ogle, 1985).

Resentment. Siblings of children with disabilities may be asked by the parents to assume household tasks and caregiving tasks that are beyond what is normally expected in sibling relationships (Grossman, 1972; Stoneman, Brody, Davis, & Crapps, 1988; Stoneman, Brody, Davis, Crapps, & Malone, 1991). The type and amount of caregiving responsibilities may be one source of sibling resentment. For others, feelings of resentment arise as siblings reflect on unjust discipline for behaviors displayed towards their siblings with disabilities, while feeling ignored and unappreciated (Powell & Ogle, 1985). Siblings might sense different expectations for appropriate behavior that parents hold for their children.

Pressure. Research supports the notion that siblings of children with disabilities may feel pressure to compensate for their parents' disappointments by over-achieving (Powell & Ogle, 1985). In a study conducted by Seligman (1983), some parents admitted to pressuring their children without disabilities to make up for their children with disabilities' limitations.

Loneliness. Preschoolers having siblings with disabilities may be at risk for perceiving reduced contact with parents as a form of "emotional rejection" or "abandonment," particularly during prolonged hospitalizations of siblings for medical treatment (Knaff & Dixon 1983; Linday & MacCarthy, 1974; Sourkes, 1980). Preschoolers may be frightened with the notion of their parents and siblings not returning, or that their parents will be unavailable to assist them during crisis situations (Koch, Hermann, & Donaldson, 1974).

Need for Honest and Accurate Information

The sense of loneliness that preschoolers of siblings with disabilities experience may be complicated by their lack of information regarding their siblings' disabilities. Current research suggests that some parents are unsure of what information is appropriate for their childrens' ages; however, siblings have a need for honest, precise, and understandable information regarding their siblings with disabilities, their parents, family issues, treatment for their siblings, and other critical issues (Edmundson, 1985; Fischer & Roberts, 1983; Lobato, 1993; Powell & Ogle, 1985; Simeonsson & Bailey, 1986; Turnbull & Turnbull, 1990). Kopriva, Turner, and Kopriva (1991) suggested that parents and service providers focus on providing different forms of information to children having siblings with disabilities, as they progress through various stages of their lives. For example, preschoolers might obtain information about their siblings' disabilities and other concerns by participating in family meetings (Townes & Wold, 1977) and participating in sibling support groups.

Interventions for Preschoolers of Siblings with Disabilities

In an attempt to increase awareness of the needs of siblings for honest and precise information and to alleviate some concerns related to siblings' lack of information or misinformation, informational and innovative group programs have been initiated for siblings of various ages (Chintz, 1981; Lobato, 1983; Miller & Cantell, 1976; Powell & Ogle, 1985). The purpose of using a group format was to "increase siblings' understanding of their brother's or sister's medical and developmental problems and related treatments in order to dispel any misconceptions about etiology and personal responsibility and vulnerability" (Lobato, 1993, p. 91). For example, Brothers, Sisters, and Special Needs designed by Debra Lobato (1990), is an explicit curriculum and activity guide for

helping young siblings, ages 3-to-8 years, of children with chronic illnesses and developmental disabilities. Parents and educational professionals are provided with the tools to address siblings' needs within the family. Siblings are encouraged to share their feelings and experiences using such techniques as puppet dialogue, demonstrations, stories, follow-up questions, and verbal praise. Additionally, the book provides a glossary of definitions of medical and developmental problems in language that young siblings can understand. Guidelines are suggested to assist adults when talking to young siblings and providing for their specific needs.

The Rationale for This Study

As an educational consultant in the field of special education, I have, over the last 3 years, worked with families who have encountered a host of problems requiring personal and social support. Fortunately, many of these families having children with disabilities are accessing educational materials, personal support, and social support via a transdisciplinary team of parents, educational professionals, social service professionals, and medical professionals.

Recently, I have encountered an increasing number of families expressing concerns over their children without disabilities, particularly preschoolers. More specifically, parents have described situations where their preschoolers displayed aggressive behaviors towards their siblings with disabilities. Other parents expressed concerns over unsuccessful attempts at providing understandable information regarding their siblings' condition, expectations for appropriate behavior, and explaining the amount of time they need to spend with their children with disabilities. At the same time, however, I have encountered families where the preschool-aged siblings without disabilities did not display any observable negative effects from having a sibling with a disability. In fact,

parents described their preschoolers as compassionate, empathic, and proud of their siblings with disabilities. These parents emphasized the importance of open, age-appropriate, and honest communication between parents and their children without disabilities.

As an educational professional working with families, it is my opinion that we, as service providers, should continue to gather more information on preschoolers of siblings with disabilities in order to have a better understanding of the adjustment phenomenon described by many families and discussed in the literature. Additionally, we need to provide preschoolers of siblings with disabilities with the understanding and support provided to parents during the intervention process. The personal reasons for pursuing this study originates out of an interest to establish more competence in an area that I perceive as important to the families I work with and support.

The Research Questions

This study was designed to answer the following questions:

1. What are parents' perceptions of the needs and concerns of families having children with disabilities and preschool-aged children without disabilities as identified during the survey, and during the follow-up telephone interview?
2. What are parents' perceptions of the needs and concerns of their children with disabilities, and their preschool-aged children without disabilities as identified during the survey, and during the follow-up telephone interview?

Definition of Terms

DISABILITY: In this study, the term disability refers to children who experience " sensory, motor, neurological, intellectual, physical, emotional, or behavioral difficulties. Examples of disability conditions include autism, behavior disorders,

cancer, Down Syndrome, mental retardation, multiple handicaps, and traumatic brain injury" (Itzkowitz, 1989, p. 14).

NEED: The term need refers to "circumstances requiring some course of action; want, requirement" (The New Lexicon Webster's Encyclopedic Dictionary, 1988, p. 669).

PARENT: In this study, "parent" is used to refer to all caregivers of children including birth parents, adoptive parents, and foster parents.

PRESCHOOL - AGED SIBLINGS: In this study, preschool-aged siblings refer to children who are between the ages of 2 years, and 5 years 6 months.

SIBLING: The term sibling refers to "one of two or more children having one or both parents in common" (The New Lexicon Webster's Encyclopedic Dictionary, 1988, p. 923).

Significance of the Study

Current literature addressing the impact of individuals with disabilities on siblings is provided in short stories and articles by parents, adolescent siblings, and adult siblings. Also, there are observational studies on interactions between preschool-aged siblings, as well as caretaking and teaching roles for preschoolers of siblings with disabilities. However, inadequate literature exists on procedures for identifying current needs and concerns of preschool-aged siblings of children with disabilities.

It is the intent of this researcher to contribute to the existing knowledge in the following areas:

1. Identify needs and concerns of families having children with disabilities and preschool-aged children without disabilities, as perceived by the parents.

2. Identify needs and concerns of preschool-aged children with disabilities, as perceived by the parents.
3. Identify needs and concerns of preschool-aged siblings of children with disabilities, as perceived by the parents.
4. Identify the positive effects of a child with a disability on a brother or sister without a disability, as identified during the telephone interview.
5. Discuss the quantity and quality of interactions between the child with a disability and his/her sibling, and the parents involvement in facilitating positive interactions, as identified during the telephone interview.
6. Identify a number of references that would be useful for families of preschool-aged children without disabilities requiring understanding, support, and a need for accurate information.
7. Provide professionals with current data regarding the needs and concerns of preschoolers of siblings with disabilities, and the family as a unit.

Summary

As the background information suggests, the need for honest and accurate information, attention, understanding, and support for preschool-aged siblings of children with disabilities, has placed these children at higher risk for behavioral maladjustment than older siblings. However, recognizing their unique needs and experiences is the first step toward improving their adaptation and development. In Chapter 2, Review of the Related Literature, the researcher discusses sibling relationships within the context of the family, and the direct and indirect effects that the family has on sibling relationships. Chapter 3 describes the methods and procedures employed in this study. A description of participants, the survey instrument, descriptive procedures, and telephone interview procedure are included in this chapter. Chapter 4 includes a summary of the results from the

survey and telephone interview. Chapter 5 includes a summary of the study, a discussion of the results, limitations of the study, and recommendations for future research.

CHAPTER 2

Review of the Related Literature

> Because Brian was only two when Daniel was born, he did not have expectations of a chattering lively playmate, so he accepted each of Daniel's problems in turn as part of the adventure of having a baby brother. By the time it became apparent that Daniel would not be like other babies, he was so thoroughly a part of the family that Brian just continued loving him the way he was. (Schmalz, 1982, p.51).

> Being the sister of a special child makes me feel proud. Sometimes it can be hard because they get most of the attention. When they do something new I feel proud because they can't do much and when they learn to do something new, it makes me happy. Sometimes it's so hard having Colleen the way she is. I just can't play with her the way other kids play with their little sisters. But I am glad to just have her. (Zalenski, 1992, p.6)

One of the most unique, eminent, and intense relationships within the family system is sibling relationships. For many children, brothers and sisters provide an unconditional source of companionship, assistance, and emotional support revealed in the frequency with which they interact at home and in the quality of their interactions. Bank and Kahn (1982) defined sibling relationships as a "connection between the selves, at both the intimate and the public levels, of two siblings; it is a 'fitting' together of two peoples' identities" (p.15). Dunn and Kendrick (1982) described sibling relationships as one of the most powerful, long-lasting human relationships, characterized by a wide range of emotional responses that can quickly change from warm to hostile and back again. Evidently, in many sibling relationships, the bond is warm, supportive, and positive. Siblings share many interests and mutual understandings; as such, sibling relationships have been described as containing elements of direct

"reciprocity" and elements of "complimentarity" (Atkins, 1989; Dunn, 1983).

Unlike typical sibling relationships, siblings of brothers and sisters with disabilities may not have opportunities to benefit from reciprocal and complementary interactions (Dunn, 1983), especially when the siblings are younger and have more caregiving responsibilities than children of the same age without brothers and sisters with disabilities. In fact, Atkins (1989) stated that siblings in these situations often experience a number of adverse feelings towards their brothers and sisters with disabilities. For example, children who grew up with brothers and sisters with disabilities recall feelings of anger, guilt, jealousy, and resentment for the number of responsibilities they had, as well as the quantity of time their parents spent with their brothers and sisters with disabilities. However, other siblings of brothers and sisters with disabilities were described as having more warmth, compassion, empathy, patience, understanding, and tolerance as a result of growing up in these families (Powell & Ogle, 1985). McHale and Gamble (1987) concluded from their findings that children of siblings with disabilities grew up in family environments which presented many unique challenges. However, " the stresses and problems children encounter seem surmountable. Long-term consequences are generally by no means negative; rather, taking on family responsibilities seems to foster greater maturity and keener awareness of the needs of others" (p. 145 - 146).

It is critical that educational professionals working with families having children with disabilities, attend to the needs of the siblings without disabilities. In order to understand the nature and quality of sibling relationships, as well as the risk factors and issues, concerns, and feelings of these children, service providers need to look within the context of the whole family (Atkins, 1989). In the following sections, a review of the existing literature examines the

development and socialization of sibling relationships within the family. Numerous studies that presented potential influences, from both within and outside the family on sibling relationships are reviewed. The researcher uses the Family Context Model (Stoneman & Brody, 1993) as a framework in which to examine literature on sibling relationships within the context of the family. Key parts of the model which are reviewed include: (a) characteristics of individual siblings, (b) characteristics of the family in which the children live, and (c) childrearing strategies used by the childrens' parents or primary caregivers. Additionally, the impact of individual parent characteristics and family temperament on parenting skills are reviewed.

The Family Context

Research supports the notion that sibling relationships do not occur in isolation (Barber, Turnbull, Behr, & Kerns, 1988; Bubolz & Whiren, 1984; Dunn, 1983; Longo & Bond, 1984; Stoneman & Brody, 1993). Sibling relationships develop against a myriad of complex and interconnected relationships within the family. As such, it is difficult for educational professionals to understand the variability in sibling relationships without examining the family as a system of relationships in which siblings are socialized. Within this system exists a set of different subsystems that mutually influence one another (Barber et al., 1988; Stoneman & Brody, 1993). For example, a nuclear family with three children may be divided according to four subsystems: (a) husband and wife interactions, (b) parent and child interactions, (c) sibling interactions, and (d) "extra - familial (total family or individual relationships with extended family, friends, community, and professionals) interactions" (Barber et al., 1988, p.186). Although the relationships within these subsystems are different, changes that occur in one subsystem affect the entire family system. Likewise, experiences of one family

member may affect all family subsystems.

The Family Context Model (See Figure 1), developed by Brody and Stoneman (1993), outlines the differences in sibling relationships where one child has a disability or chronic illness. Attributes specific to each sibling, the family system, and parenting strategies are identified as having a direct impact on sibling relationships. In addition, since the family system consists of interconnected subsystems, caregiving strategies are influenced by attributes of the parents, of individual siblings, and the "emotional climate" of the family (Stoneman & Brody, 1993, p.4).

Insert figure 1 about here

In an attempt to explain the socialization of sibling relationships within the family, Stoneman and Brody (1993) developed and discussed the following five key components of their Family-Context Model: (a) characteristics of the individual siblings, (b) the effects of individual sibling characteristics on parenting, (c) the effects of individual parent characteristics on parenting, (d) the effects of family characteristics on parenting and on the sibling relationship, and (e) parenting and the sibling relationship. For purposes of this study, the literature review mainly focuses on the direct influence of individual child characteristics on sibling relationships. These characteristics are also reviewed as an indirect influence on sibling relationships through their effects on parenting.

Individual Sibling Characteristics

Stoneman and Brody (1993) identified eight disability-related variables which might affect sibling relationships: (a) age, (b) gender, (c) temperament, (d) care demands, (e) serious health risks, (f) cognitive/language competence, (g) social/adaptive competence, (h) physical or sensory disability, (i) aggression,

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Figure 1. Sibling relations in the family context. (Most paths are bidirectional. Only direct and indirect effects on the sibling relationship are included in the figure.)

Note. Figure taken from "Sibling Relations in the Family Context" by Z. Stoneman, and G. H. Brody. *In The Effects of Mental Retardation, Disability, and Illness on Sibling Relationships* (p. 10) by Z. Stoneman and P. Waldman Berman (Eds.), 1993, Baltimore: Paul H. Brookes Publishing Company., Inc.

and (j) noncompliance. For purposes of this section, age, gender, and birth order are grouped together as the researcher discusses the variation in the quality of sibling relationships. Although temperament was identified as a disability-related child characteristic affecting sibling relationships, child temperament is included in a following section discussing the effects of individual sibling characteristics on child-rearing strategies. Child temperament is examined in terms of how it may potentially affect the sibling relationships through it's impact on parenting.

Care demands.

> I first remember having a sense of special responsibility for my sister when I was three. It was my duty to keep her out of danger and mischief - a seemingly normal responsibility for an older sister. But the responsibility has at times felt unbearably heavy. As a two-year-old, Mindy was not only typically rambunctious, she lived in a bizarre and often dangerous world all her own-separated from the rest of us by her deafness and her inability to communicate. (Hayden, 1974, p.26)

One of the variables identified as having a negative impact on sibling relationships is the type and quantity of caregiving responsibilities and household chores that siblings without disabilities are frequently asked to assume for their brothers and sisters with disabilities (Crnic & Leconte, 1986; Farber, 1960; Farber & Jenne, 1963; Gath, 1974; Gath & Gumbey, 1987; Grossman, 1972; Rowitz, 1993; Seligman, 1983; Stoneman et al., 1988, 1991). Some children in these situations were reported as experiencing a number of adverse feelings towards their brothers and sisters with disabilities (Atkins, 1986; Holt, 1976; Simeonsson & McHale, 1981; Stoneman et al., 1988). For example, children who grew up with brothers and sisters with disabilities recalled feelings of anger, guilt, jealousy, and resentment for the number of responsibilities they had as well as the quantity of time their parents spent with their siblings with disabilities. Conversely, other siblings having brothers and sisters with disabilities were

described as having more warmth, compassion, empathy, patience, understanding, and tolerance as a result of growing up with and providing care for their siblings having disabilities (Powell & Ogle, 1985). This section includes a summary of results from studies investigating the potential concerns with increased caregiving and household activities performed by siblings of children with disabilities on sibling relationships.

Research indicates that first born sisters of children with disabilities assume greater responsibility for caregiving and household tasks than either a first born male or a later born female (Cleveland & Miller, 1977; Correa, Silberman, & Trusty, 1986; Gath, 1974; Lobato, 1983; McKeever, 1983; Trevino, 1979). Additionally, younger siblings of brothers or sisters with disabilities were reported as being at risk for maladjustment since they might be expected to assist with caregiving activities they would not otherwise perform. McKeever (1983) stated there was a "perceived change in ordinal position for this child with the handicapped child being treated as younger than he or she really is, and a concurrent role strain for the sibling" (p. 210).

In an attempt to understand the amount of frustration, tension, and/or anxiety experienced by siblings who assume responsibilities for their siblings with disabilities, studies were conducted to investigate the amount of time siblings of children with disabilities spend on household and caregiving responsibilities. Lobato, Barbour, Hall, and Miller (1987) utilized a questionnaire based on Schwirian's questionnaire (1977) to investigate caregiving and household responsibilities as well as home privileges and restrictions. Mothers were asked to rate the extent to which their children without disabilities engaged in caregiving activities (e.g., assisting with dressing, bathing) and household activities (e.g., domestic activities). On the home privileges and restrictions subscale,

mothers were requested to utilize a 0 to 40 scoring scale, where higher scores indicated more restrictions and fewer privileges (e.g., set bedtime, controlled television viewing) (Lobato et al., 1987). Results indicated that sisters of children with disabilities had the greatest degree of responsibility for household and caregiving activities when compared to children with disabilities and siblings of children without disabilities; however, there were no significant statistical differences. The scores on the privileges and restrictions subscale, suggested that parents may respond to the presence of a child with disabilities by increasing the "expectations and demands on daughters while relaxing those placed on sons" (Lobato et al., 1987, p. 337).

Stoneman et al. (1988) interviewed mothers and older siblings of children with and without disabilities independently using an adapted version of an instrument developed by Schwirian (1977). The instrument contained questions regarding caregiving responsibilities, household activities, contact with peers, and extra-curricular activities. The researchers reported that older sisters of children with and without disabilities had significantly more responsibilities in domestic activities while older brothers had significantly more responsibilities in outdoor chores (e.g., yard work). It has been found that older sisters of children with disabilities had the greatest amount of responsibility for babysitting and caregiving activities than any of the other four groups (Cleveland & Miller, 1977; Correa et al., 1986; Gath, 1974; Lobato, 1983; McKeever, 1983; Trevino, 1979). In addition, correlational analyses for siblings of children with disabilities, revealed greater caregiving activities associated with less observed positive interactions between siblings and more sibling conflicts.

In a similar study with younger siblings (range from 4 to 10 years with mean of 6.5) of children with and without mental retardation, Stoneman et al. (1991)

concluded that younger siblings of children with mental retardation participated in caregiving responsibilities. The caregiving responsibilities included assisting with dressing, feeding, and babysitting, with sisters performing significantly more household activities than brothers of siblings with mental retardation. In addition, younger siblings responsible for caregiving activities acted more as the helper during recreational activities with their brothers and sisters with mental retardation. Consequently, the researchers reported that reciprocal and complimentary role relationships between siblings were less common when younger siblings were actively involved in day-to-day physical care of their siblings, and when younger siblings perceived their childcare tasks to be greater than those of friends (Stoneman et al., 1991).

Current research supports the notion that there are large individual differences in the types and amounts of caregiving and household activities. Stoneman et al. (1987) stated that siblings of children with disabilities may be negatively affected when these responsibilities are great. However, the effects of caregiving and household activities appear to be related to the gender and age of siblings of children with disabilities, and the type, frequency, and magnitude of caregiving, and household responsibilities. Interestingly, the researcher was unable to find any well controlled research studies to support the notion of young siblings of children with disabilities being responsible for and/or adversely affected by heavy amounts of care-giving duties for their brothers and sisters. In addition, it is possible that care-giving duties of younger siblings of children with disabilities may not have a negative effect on social interactions between these siblings.

Health risks.

> Thomas' skills are so sporadic that it is hard to create some sort of certainty for Erika. Some days he will look at her or accept a toy from her, but it may not happen again for weeks. If Thomas plays with the wagon one day, and Erika says, "He did it, Mommy," it does not mean he will do it again, or that he will build on that skill. It means that Erika must adjust to a lot of ups and downs. Erika must "punt," and adjust constantly to things she cannot even comprehend. (Post, 1991, p.17)

Play is considered to be a primary medium through which all children acquire social, physical, and cognitive skills; therefore, the opportunity to play is important for all children. Given the importance of social interaction in play, it is no surprise that play between siblings with and without disabilities is especially important. Pepler et al. (1984) stated, " the extensive contact, intimacy, and familiarity between siblings may promote a high level of social interaction and an opportunity to engage in complex and successful social interactions at an earlier developmental stage than is possible with less familiar playmates" (p. 20).

Stoneman and Brody (1993) asserted that siblings of children with disabilities and serious health problems (e.g., chronic health problems, seizures, heart problems, frequent hospitalization) may have difficulties playing with their brothers and sisters. For example, siblings of children with a disability and a serious heart condition may refrain from initiating play activities involving physical contact. In addition, the increased probability of death of a sibling with a life-threatening condition may directly influence the quantity and quality of siblings' play and social interaction with their less healthy brothers and sisters.

Although increased health risks may negatively affect sibling relationships, no current empirical evidence could be found to support the negative impact of health risks on the quantity and quality of play interactions between children with disabilities and their siblings.

Cognitive and language competence.

> We see Erika feel sad and rejected when Thomas pushes her away. We see her try to make sense of it all when she looks at us and says, "Thomas no talk, Mommy." We see her rejoice in the small interactions Thomas sometimes attempts. Since she is so young, it is difficult to talk extensively about her feelings. We ask her if she feels sad or mad, and sometimes she nods or admits, "I'm mad at Thomas." I think in some way she understands that Thomas just can't do some things. (Post, 1991, p. 18)

Stoneman and Brody (1993) suggested that children with minimal cognitive and language competence may have difficulties initiating and interacting within a social context for extended periods of time with their siblings and peers. For example, in two studies conducted by Stoneman et al. (1988, 1991), children with mental retardation and minimal language competencies were identified as having difficulties participating in cooperative play and play involving higher level cognitive skills (e.g., board games) with their siblings without disabilities. In fact, "the more severe the skills deficit of the child with mental retardation, the larger were the discrepancies between his or her play levels and those of the older sibling, and the harder these discrepancies appeared to be for the children to overcome" (Stoneman & Brody, 1993, p. 13).

Social and adaptive competence.

> Often, one parent must become Erika's playmate. We play the games with her that Thomas cannot play, and talk about things they cannot discuss together. When we see Erika play so joyfully with her peers without disabilities, we realize how much of a relationship she has lost with Thomas. (Post, 1991, p.18)

A person's success, and happiness are largely determined by his or her ability to interact effectively with other individuals. Although the development of social competence is important in and of itself, it also affects the development of cognitive and communication skills (Odom, McConnell, & McEvoy, 1992). Furthermore, research has illustrated that social competence is relatively stable

throughout childhood and adolescence, underlining the importance of promoting social skill development in young children (Hartup & Moore, 1990; Parker & Asner, 1987).

Many children with disabilities typically fail to develop adequate social competence, especially in relation to their peers and siblings. In fact, early interventionists have reported that approximately 75% of their students needed to learn more positive and age-appropriate ways to interact with others (Odom et al., 1992). Further research found that children with disabilities established no reciprocal interaction patterns, and even when they displayed peer preferences, these were not reciprocated by the chosen peer (Guralnick & Groom, 1988).

Consistent with this research, Stoneman et al. (1991) concluded that children with mental retardation had fewer opportunities for social interaction as compared with same-age peers without disabilities. In fact, the researchers reported that "these children had fewer friends visit them at home, went less often to the homes of friends to play, and participated in fewer out-of-home activities" (p. 549). As children, the inability to establish and enjoy socialization experiences may result in unsuccessful attempts at establishing community-based friendships.

Over the years, siblings with and without disabilities have spent a great deal of time together and, in doing so, have come to share many unique experiences (Bank & Kahn, 1982). Some studies have shown advantages to having children with disabilities socialize and play with their siblings. In these situations, children with a disability's behavior may be more social and more appropriate than it is when they participate in solitary play or play with other children having disabilities (Mash & Mercer, 1979). However, for siblings of children with disabilities, play experiences may not be as enjoyable, especially when their brothers and sisters

have poor adaptive skills. McHale and Gamble (1987) used a telephone diary procedure to access information about the type, quantity, and quality of sibling interactions between children of siblings with disabilities, and poor adaptive competencies, as perceived by their mothers. Results indicated that siblings without disabilities attempted to entertain, take care of siblings, or teach them new skills. Consequently, these researchers were concerned that children of siblings with disabilities " may not experience the same degree of emotional support, sharing of perspectives, and give and take that they would if their siblings were more similar in mental, emotional, and social development" (McHale & Gamble, 1987, p. 144). Similar results were reported in a study that utilized naturalistic family observations to investigate social interactions between siblings, where one sibling presented with mental retardation and poor adaptive skills (Stoneman et al., 1987; 1989). The researchers found that children with more advanced adaptive skills participated in more cooperative play activities with their siblings and more reciprocal sibling role relationships. Evidently, the development of sibling and peer related social competence has important, life-long implications, and should, therefore, be a major focus of early intervention.

Physical or sensory disability. Although this researcher could find no sound empirical evidence supporting the notion that sibling relationships may be negatively affected when one sibling presents with a sensory disability, Stoneman and Brody (1993) suggested that a vision and/or hearing loss might limit the types of play activities that the siblings could participate in together.

Two articles were identified as specifically addressing children with visual impairments and their siblings. A study conducted by Lavine (1977) used observational procedures to study the interactions between siblings of children with visual impairments. The researcher concluded that siblings of children with

visual impairments developed age-appropriate and socially appropriate relationships with their siblings with visual impairments. In addition, the researcher made note of the influence of parents' expectations on the behaviors and attitudes of the siblings with disabilities.

Steinzor (1967) interviewed 16 children of siblings with visual impairments. Although the children were reported as having no problems adjusting to siblings with visual impairments, the study also reported that these children had minimal information on blindness and were uncomfortable or afraid to ask for information regarding their siblings' disabilities.

Aggression. In their observational studies, Stoneman and Brody (1993) concluded that siblings of children with disabilities do not typically reciprocate aggressive attacks towards their brothers and sisters with disabilities. However, upon review of anecdotal reports from educational professionals and parents, the authors hypothesized that the quality of sibling relationships and the amount of time spent engaging in play may be adversely affected.

Noncompliance. Noncompliance in preschoolers with disabilities has been reported as a significant behavior problem in many families (Barkley, 1987; Bernal, Klinnert, & Schultz, 1980; Patterson, 1982). More specifically, noncompliant behavior has been reported as having an adverse effect on family functioning, and the level of stress experienced by the family, particularly for siblings (Barkely, 1987). For example, a child who refuses to comply with requests specifying a behavior to be initiated (e.g., David, put your coat on) or inhibited (e.g., David, no throwing toys), may engage in more negative interactions with the parents. In a study conducted by Brunk and Henggeler (1984), a sample of mothers spent more time providing more direct commands, ignoring strategies, and less positive interactions with the children displaying

aggressive and noncompliant behaviors. Consequently, negative interactions between the parents and these children may affect the parent's self-esteem, marital harmony, and the noncompliant child's self-esteem (Barkley, 1987; Wahler & Duman, 1986).

Stoneman et al. (1991) investigated noncompliant behavior of children with mental retardation towards their siblings without disabilities. As a result of high levels of noncompliance on the part of the children with disabilities, parents were more reluctant to assign caregiving responsibilities (i.e., babysitting duties) to the younger siblings without disabilities. Additionally, the researchers proposed that negative coercive interactions between the children might have a negative impact on sibling relationships, resulting in more accentuated patterns of sibling role asymmetry.

Birth order, age-gap, and gender.

> An older sister (Susan, 97 months) directs the activities of her younger brother with Down's Syndrome (Alan, 53 months): Susan says, "Catch the ball." Susan teaches Alan how to hold his hands. Susan asks Alan to pretend he is eating. Susan pretends she's eating and Alan looks at her. Susan asks Alan to laugh. Alan does. Susan asks Alan to sleep. Alan pretends he's sleeping. Susan asks Alan to pick a stick up. Alan does. Alan pretends he is drawing. Susan teaches Alan how to hold his fingers to pretend he's drawing. Alan imitates. (Pepler, Stanhope, Crozier, 1984, p. 24)

Although there is limited research describing the quality of interactions between typically developing preschool-aged siblings, a few experimental studies suggest that from the first months of life onward, almost all children spend a great deal of time watching, paying attention to and interacting with their siblings. Lamb (1978) observed 24 infants at 12 months with their preschool-aged siblings, and completed follow-up observations 6 months later in the same settings. The researcher discovered that the infants followed by observing and

imitating while the preschool-aged siblings "led" by drawing the infants' attention and by "assertive dominance" (p.1189). To substantiate these observations, researchers provided evidence suggesting there was a higher probability that infants typically were not only interested in their siblings but were far more likely to imitate and identify with siblings as models (Edwards & Lewis, 1979; Lewis & Brooks-Gunn, 1979; Rubenstein & Howes, 1976; Vandell, Wilson, & Buchanan, 1980). A Canadian study conducted by Pepler, Corter, and Abramovitch (1982) concluded that 27% of all interactions between the 20-month-old second born children and their older siblings were imitative and this pattern continued in follow-up studies. The high frequency of imitation of older siblings by second-born children provided support for the "saliency of the elder child as a model for the younger; exchanges in which each child imitates the other playing a significant part in communicative sequences between the children, a part that underlies the rapport and mutual interest between the children and highlights the reciprocal features of their relationship" (Dunn, 1983, p.792).

As researchers became interested in the quality of interactions between typically developing siblings of all ages, variables such as birth order, age-gap, and gender were examined to see if they played a critical role for the uniqueness and diversity in relationships between brothers and sisters without disabilities (Brody & Stoneman, 1990; Dunn, 1983; Minnett, Vandell, & Santrock, 1983; Sutton-Smith & Rosenberg, 1970). Researchers have also attempted to investigate these variables as they pertain to sibling pairs where one child has a disability (Crnic & Leconte, 1986; Gallagher & Powell, 1989; Hannah & Midlarsky, 1985; Simeonsson & McHale, 1981). In the following section, a review of the aforementioned variables that may influence patterns of sibling interaction across typically developing siblings are reviewed. Subsequently, a brief review of

current studies designed to investigate the influence of some of these variables on siblings' reactions to living with brothers and sisters with disabilities is presented.

Dunn, Bruner, Cole and Lloyd (1985) stated, "in some families every interaction is warm, supportive, playful, and affectionate" (p. 166). As a result, first born children in these families had the ability to function as excellent models for developing and enhancing communication, social, and sociocognitive skills while the younger child functioned as the learner (Dunn, 1983). However, according to Furman and Buhrmester (1985), warm and supportive relationships were typically found with same sex siblings with a small age gap between them. Observational studies on the interactions between first born children and their siblings who were 3-to-4 years younger, were typically more positive (i.e., cooperative and affectionate), particularly when the older child was teaching his/her younger brother/sister (Minnett et al., 1983).

Unfortunately, in some families, brothers and sisters were constantly aggressive and hostile towards each other, particularly those siblings close in age (Furman & Buhrmester, 1985). A study examining the interactions between 7-to-12 year old brothers and sisters conducted by Minnett et al. (1983) concluded that first born children were more aggressive than siblings that were close in age, particularly same sex-siblings. In addition to aggressive interactions between same sex-siblings, Minnett et al. (1983) identified "cheating and dominance as more characteristic of the childrens' behaviors with same sex-siblings than with an opposite sex-sibling" (p. 1065).

Unlike the results collected in the former studies, Abramovitch, Corter, Pepler and Stanhope (1986) did not find age-spacing effects and found more positive interactions for mixed gender dyads. However, observations on the interactions

between infants and preschoolers took place in the home with the mother present, suggesting that "marked individual differences in the quality of their behavior toward each other might be associated with variables other than age of the first child when the sibling is born" (Dunn, 1983, p. 803).

Current literature provides interesting and conflicting evidence for gender differences in typically developing preschoolers' behaviors toward their brothers and sisters. A follow-up study by Abramovitch et al. (1986), identified younger siblings as seeking comfort, assistance, and security more frequently from older sisters than older brothers; especially when the younger sibling is a girl. Many first-born girls participated in caretaking activities when the brother or sister was 8-to-14 months (Dunn & Kendrick, 1981). These studies might have suggested that girls were more likely to be more nurturant than boys; however, there was no conclusive evidence for older sisters as more nurturant and better teachers than older brothers. Simply stated, "sex differences in either younger or older siblings cannot be linked in a simple or powerfully predictive way to differences in the way children relate to one another" (Dunn et al., 1985, p. 79).

Relationships between children with disabilities and their siblings may not be that different from the quantity and quality of social interactions between siblings without disabilities. Information collected from observational studies and home visits with questionnaires concluded that the quantity and quality of social interactions between siblings of children with disabilities were just as high as interactions between siblings of children without disabilities (Abramovitch, Stanhope, Pepler, & Corter, 1987; Brody, Stoneman, & Burke, 1987; Stoneman et al., 1989). However, McHale and Gamble (1989), concluded that sibling relationships between siblings of children with disabilities were more likely to be "asymmetrical." In fact, although social interactions between these siblings were

reported as being positive and high, the siblings without disabilities were described as taking on teacher, manager, or caregiver roles. Research studies investigated the type and amount of caregiving and teaching responsibilities in combination with gender, age, and birth order of the siblings of children with disabilities. For example, as stated in an earlier section, many siblings assumed caregiving duties for their brothers and sisters with disabilities (McHale & Gamble, 1989; Seltzer, Begun, Seltzer, & Krauss, 1991; Stoneman et al., 1988). Researchers were interested in investigating the frequency in which older sisters and younger sisters managed and directed more frequently in their relationships with younger siblings than their brothers. Wilson, Blacher, and Baker (1989) concluded from their study of siblings of children with disabilities that gender did not correlate with caregiving and household duties. With respect to age, Begun (1989) reported more sibling conflicts between adolescent-aged sisters and their brothers and sisters with mental retardation than adult-aged sisters. Regarding birth order, researchers investigated the effect of birth order of the siblings of children with disabilities on sibling relationships. On measures of self-concept, attitudes towards children with mental retardation, and vulnerability to aggressive behaviors, some researchers found no conclusive evidence to support birth order as having a negative influence (Dyson & Fewell, 1986; Gath & Gumley, 1987). However, it was interesting to note that in the study conducted by McHale, Sloan, and Simeonsson (1986) younger siblings of children with disabilities indicated greater feelings of rejection toward their siblings with disabilities than older siblings of children with disabilities.

Although there were a number of methodologically sound research studies addressing the effects of birth order, age and gender on the interactions between sibling dyads, researchers were careful not to generalize their observations and

experimental results to all siblings. There were many inconsistencies in the literature due to the number and different ages of children studied, clinical vs. natural settings for observations, methods and procedures used, and different cultural backgrounds of the families studied. Also, most of these studies examined families where siblings of brothers and sisters with disabilities were often of the same gender and usually of consecutive birth order. Consequently, researchers continue to investigate the quality of relationships between a child and parent in natural settings and the impact of parent - child interactions on sibling relationships using comparison groups and direct observation.

The Effects of Individual Sibling Characteristics on Parenting

> Parenting is never easy, no matter how ideal the family situation. The development of any healthy family depends on the ability of parents to consider the strengths and weaknesses of each member. This is highlighted when one of the children has a disability. More importantly, parents should realize and remember they are not superhuman. They are entitled to moments of doubt, pain and confusion. In recognizing and coping with these feelings, parents become stronger and, in turn, strengthen the family unit, a structure that requires all members to share their lives on an equal basis. (Michalegko, 1991, p. 22)

Much has been written about the adjustments parents must make when they learn their children have disabilities. Parents may experience difficulties adjusting to the child's disability beginning with the diagnosis (Ellis, 1989; Kopriva et al., 1991). It is possible that many parents have encountered and dealt with the following issues at the time of diagnosis: (a) altering family routines and schedules to provide immediate care for the child, (b) process the technical information from intervention specialists, (c) impact of the disability on one's values and expectations, (d) labeling, stereotyping and a sense of isolation, (e) somatic complaints that arise from family members as a result of the stress, and (f) working through their feelings of grief, anger, guilt, and helplessness (Ellis,

1989, p.260). Additional areas of need that were cited included effective and sensible use of available finances to meet the needs of the entire family and making future decisions in regards to the care and supervision of the child with the disability (Kopriva et al., 1991).

According to the Family Context Model (see Figure 1), characteristics specific to the children with disabilities may also influence parenting behaviors (e.g., disciplinary strategies, attitudes towards the child with a disability, and strategies utilized to facilitate social interactions between siblings). For example, child attributes such as aggression, temperament, noncompliance, age, and gender might have an impact on the differential behavior that parents directed toward the siblings. In the Family Context Model, Stoneman and Brody (1993) identified ten child characteristics that could potentially influence parenting. In this section, the impact of one of these characteristics, difficult child temperament, is examined.

In some family situations, difficult child temperament might affect parental childrearing strategies and attitudes, and result in differential parental behavior that "favored" one child over another. In fact, researchers have associated children who are active and emotionally intense with increased conflict with parents, ineffective teaching efforts, increased power struggles with parents, aggression and noncompliance, and lower parenting self-efficacy (Brody, Stoneman, & Burke, 1987; Buss, 1981; Cutrona & Troutman, 1986; Maccoby, Snow, & Jacklin, 1984; Mash & Johnston, 1983). Additionally, highly active and impulsive children may affect sibling relationships in different ways, depending on the ways in which parents manage their children. Some parents may relate to the children in ways that tend to increase sibling conflict, whereas others may use strategies that will reduce sibling conflict, including equal treatment of

siblings, nonintervention in sibling conflict, and clear rules and expectations for sibling behavior.

Support for the hypothesis that a child's temperament affects sibling relationships can be found in studies of children who display aggressive and other negative behaviors towards family members, particularly siblings. In a study designed to examine the influence of maternal differential behavior and sibling temperament on the sibling relationships of school-aged children, 40 mothers and their same-sex children (20 pairs of boys and 20 pairs of girls) were videotaped playing in their living rooms on two separate occasions approximately one week apart (Brody et al., 1987). The older siblings' ages ranged from 7-to-9 years, and the younger children were 4.5-to-6.5 years of age. The mothers completed selected temperament dimensions of Martin's Temperament Assessment Battery (i.e., motoric vigor, emotional intensity, and persistence). Results from this study supported the hypothesis that sibling dyads including an active, emotionally intense, or nonpersistent child were more likely to experience higher rates of aggressive behavior. Additionally, maternal differential treatment was associated with the quality of sibling relationships. The researchers concluded from their results that "it is possible that school-aged siblings expect a certain amount of differential behavior in favor of the relatively less competent younger child, and only when the amount of differential behavior becomes excessive from the perspective of either sibling does it affect the relationship" (Brody et al., 1987, p. 361). Consequently, the researchers proposed that if higher than expected levels of differential treatment were provided by parents, the siblings might adjust by decreasing the amount of time they chose to interact with one another.

Evident is the fact that children with disabilities place additional demands on

families which may stress established patterns of interaction between family members. However, the coping strategies and adaptations used by the family to manage the degree of stress imposed by these demands will determine the effect that children with disabilities have on family relationships. Breslau (1981) stated that the impact of a childhood disability on family members alters the family environment and potentially may affect the psychological functioning of the sibling without disabilities. For example, although the children without disabilities may receive similar amounts of parent attention as their same-age peers, intrafamily comparisons suggest that siblings of children with disabilities received different amounts of parental attention (Stoneman et al., 1987). As stated earlier, clinical observations suggested that because of the disproportionate care that children with disabilities may receive, younger siblings without disabilities may show more attention-seeking behaviors towards family members (Tew & Laurence, 1973).

The Effect of Individual Parent Characteristics on Parenting

> Complications during birth caused brain damage to our son, Eric, leaving him disabled. His doctors told us he was disabled before he even came home from the hospital, so the grieving process started the day he was born....Denial soon gave way to anger. I was so mad! Not just at the fact that I had a child with a disability ... I was mad at everything... the weather, friends, and doctors(really mad at doctors). It's so depressing to be depressed. I like to have fun and when depression first assaulted me, I tried to fight it by having "fun." The only problem was, I couldn't find anything fun about having a child with a disability. (Johnson, 1991, p. 46-47)

Families of children with disabilities are often faced with a unique set of challenges as they attempt to adapt to the presence of children having disabilities within the family unit. Consequently, these families may be vulnerable to the experience of stress and personal maladjustment. More specifically, parents of children with disabilities may experience increased financial difficulties resulting

from the needs for special equipment, medical care, and special programming. Other problems reported in the literature by parents included isolation and decreased social mobility, fatigue and a variety of such emotional manifestations in the parents as depression, anger, guilt, and anxiety (Cameron, Orr, & Williams, 1993; Kazak & Marvin, 1984). Extensive literature has been accumulating that links a wide variety of factors to parental stress. Stoneman and Brody (1993) identified five parental characteristics as having an impact on parents ability to cope with stressors in general, and with the more specific stressor of caring for a child with disabilities: age, gender, temperament/personality, depression, and anxiety/stress (see Figure 1).

Although a great bulk of literature concerned with parental reactions and parenting has dealt with the reactions of mothers (e.g., Barber et al., 1988; Cross, 1980; Kazak & Marvin, 1984; Stoneman & Brody, 1993), it is no surprise that both mothers and fathers of children with disabilities may experience anxiety and depression (Cameron et al., 1993; Crnic et al., 1983; Dyson & Fewell, 1986; Gallagher, Beckman, & Cross, 1983). The literature pertaining to mothers who experienced anxiety and depression while caring for children with disabilities supported the notion that these mothers displayed ineffective parenting strategies, were more likely to induce guilt and anxiety as a means of controlling their childrens' behavior, were less tolerant of their children, and were less nurturing and affectionate (Longfellow, Zelkowitz, & Saunders, 1982; Susman, Trickett, Iannotti, Hollenbeck, & Zahn-Waxler, 1985; Zelkowitz, 1982).

Stoneman, Brody, and Burke (1989) indicated that fathers of children with disabilities were also vulnerable to difficulties living with the uncertainty of their childrens' disabilities, discussing their concerns with family and friends, and supporting their wives who carried the daily burdens. Consequently, it is possible

that parent depression could have a negative impact on the quality of the sibling relationship, "mediated by the compromising effects of depression on parenting" (Stoneman & Brody, 1993, p. 20).

Finally, it seems logical that if stress associated with parenting children with disabilities was identified as an important concern, then the marital relationship would be vulnerable to the effects of increased stress as well (Kazak & Marvin, 1984). It would appear that the negative emotional states experienced by parents of children with disabilities may compromise their marriage, their parenting skills, and their ability to socialize sibling relationships.

The Effect of Family Characteristics on Parenting and on Sibling Relationships

> Our family experienced a great deal of grief and anger towards our situation. We had many questions that we did not know the answers to. We experienced fear and helplessness in our situation because we did not know what to do for our son and with our son to encourage his development because of his blindness. My other children have had to deal with resentment towards their brother because of the commitment we had to make to him. Our lifestyle changed considerably and we worried about our finances and our future. (McConnell, 1987, p. 6-7)

Families of children who have disabilities are often faced with a unique set of challenges as they attempt to adapt to the presence of children with disabilities within the family unit. As noted above, the presence of a child with disabilities is a source of stress and may place excessive demands on the energy and other resources of the family. Additional physical care and exertion may be necessary and continuous. Furthermore, locating and obtaining access to the medical, educational, social, and other support services needed may place still additional demands on the family's energy. Families of children with congenital disabilities must confront the former demands as soon as they bring their child home from the hospital (Wolfensberger & Menolascino, 1970). Stoneman and Brody (1993) identified the following family characteristics as having direct and indirect effects

on parenting and on the sibling relationships: (a) marital satisfaction, (b) parent or caregiver conflict, (c) emotional climate of the home, (d) family problem solving style, (e) family form and structure, (f) poverty, (g) financial stress, and (h) ethnicity (see Figure 1).

Among the most critical family characteristics imposing a degree of stress on the family is socioeconomic circumstances (Rabkin & Streuning, 1976; Rosenberg, 1977; Stoneman & Brody, 1993). For example, an early study conducted by Ramey, Mills, Campbell, and O'Brien (1975) investigated the home environments of children with disabilities as "at risk" for socioculturally determined retardation with a sample of children from the general population. Significant differences were identified favoring typically developing same-age peers on factors such as maternal warmth, involvement, absence of restriction and punishment, organization of the environment, appropriate toys, and opportunities for variety. Interestingly, the authors proposed that a possible reason for the findings was that the families with difficult socioeconomic circumstances may expend much time and energy maintaining the household, locating personal, medical, and financial support services, and managing day to day routines (Ramey et al., 1975). Mothers, in particular, have been identified as the family member who is physically and emotionally exhausted because of extra demands made on her time and energy (D'Alonzo & Lazar, 1991). Consequently, parents may find that they have little energy left to share with their children.

The literature on marital relationships suggested that families with children having disabilities might be more likely to experience marital conflict and divorce (Belsky, 1984; Brody, Pellegrini, & Sigel, 1986; Callan & Noller, 1986; Goldberg & Easterbrooks, 1984). Some studies attempted to investigate the relationship between marital conflict and challenging behaviors displayed by the children in

the family (Block, Block, & Morrision, 1981; Emery & O'Leary, 1984; Whitehead, 1979). Each study concluded that there was a strong relationship between marital difficulties and challenging behaviors displayed by the children in the family, particularly the boys. However, the researcher found no evidence to support a relationship between parents' marital conflict and child functioning.

It seems logical that if stress is associated with parenting a child with disabilities, and the parents are dissatisfied with their marriages, then the marital relationship, parent-child relationship, and sibling relationship would be vulnerable to the effects of that increased stress as well (Belsky, 1984; Brody, et al., 1986; Callan & Noller, 1986; Goldberg & Easterbrooks, 1984; Forehand, Long, Brody, & Fauber, 1986; Long, Forehand, Fauber, & Brody, 1987). Parents might have difficulties implementing strategies that foster equal treatment of the siblings, refrain from intervening in their childrens' conflicts, and experience difficulties with setting clear rules and expectations for sibling behavior (Block, Block, & Gjerde, 1986; Block et al., 1981; Emery & O'Leary, 1984; Heatherington, Cox, & Cox, 1981; Patterson, 1980). Although there was contradictory evidence as to whether the presence in the family of a child with a disability had a negative effect on the marital relationship (Morgan, 1988), it is probable that based on the previous findings, stressed marital relationships may have negative ramifications for parenting, and, indirectly, for sibling socialization (Stoneman & Brody, 1993).

Parenting and the Sibling Relationship

It is not surprising that parent-child relationships can significantly affect the way preschool-aged children react to growing up with brothers and sisters with disabilities. Stoneman and Brody (1993) commented that " the manner in which parents socialize their individual children, as well as the manner in which they

socialize the sibling relationships, affects the quality of interactions between siblings, as well as the roles that they assume" (p. 25). Although preschool-aged children may encounter challenges while playing and/or providing some care for their brothers and sisters with disabilities, these challenges may not result in adverse feelings or behaviors towards them. Many parents encourage open communication with their children to discuss questions, worries, and/or concerns. In addition, many siblings have been taught how to manage difficult situations (e.g., sibling conflict) with their brothers and sisters with disabilities. Both parents and professionals help these siblings of children with disabilities to cope in effective ways, and facilitate opportunities for assisting these children with developing as close to typical and age-appropriate relationships with their brothers and sisters with disabilities as possible.

The Family Context Model includes the following six strategies to assist parents in facilitating positive social interactions between sibling pairs, where one sibling has a disability: (a) direct parent behavior toward each child, (b) childrearing strategies, (c) differential parental attention/behavior, (d) consistency, (e) sibling socialization practices, and (f) sibling socialization goals. Each strategy is briefly described in the following section.

Direct parent behavior toward each child. Stoneman and Brody (1993) stated that positive interactions between siblings, in general, are influenced by the types of interactions between the parents and the children. Certain styles of parental behavior toward their children may encourage supportive and affectionate interactions between siblings. For example, open communication, explaining feelings and actions, and taking time to focus on the importance of helping one's brother or sister may encourage a more harmonious relationship between the siblings. In addition, parents may set up play situations where their children

acquire, maintain, and generalize prosocial skills (e.g., cooperation, turn-taking, empathy) needed to develop quality relationships between parents and their children, and between the siblings.

Childrearing strategies. The type of discipline used by parents to "socialize" each child may influence the quality or relationships between the siblings (Stoneman & Brody, 1993). For example, parents using nonaversive discipline strategies may create an environment for positive prosocial interactions between siblings. Honest communication, clear expectations for appropriate behavior, praising children for appropriate behavior, and logical consequences are examples of childrearing strategies used by many parents to meet their needs and the needs of their children.

Childrens' behavior varies greatly, both between children of the same age, and between different ages for the same child. If parents have unrealistic expectations of the children with and without disabilities, they may waste much time and energy attempting to achieve the impossible, and discourage the parents and children in the process. Siblings of children with disabilities may be provided with positive strategies for managing their brothers' and sisters' inappropriate behaviors in an appropriate way, and manage their own reactions to problems that may occur while playing or assisting their brothers and sisters with disabilities. Cognitive behavioral strategies are one example of positive strategies suggested for teaching siblings how to define problems and brainstorm positive solutions.

Differential parental attention/behavior. One potential source of conflict for siblings of children with disabilities is that expectations for appropriate behavior and household responsibilities may be different than those of their brothers and sisters with disabilities. Stoneman and Brody (1993) stated that differential

treatment from the parents may contribute to the quality of sibling relationships. They suggested that sibling pairs, where one sibling has a disability, be treated as brothers and sisters first. Parents were advised to encourage their children with disabilities to be as independent as they are physically able, and contribute to the family to the best of his or her abilities.

Consistency. Stoneman and Brody (1993) suggested that both parents try to respond to inappropriate behaviors displayed by all their children in a predictable way. When parental intervention is needed, many parents are most effective by acting firmly, calmly, and predictably. For example, if a child is warned that he must "play with his toys in the water basin or the toys will go away," then every time the child throws the toys out of the basin, the toys will need to be put away for a period of time. If the child is permitted to play with the toys in this manner, then the effectiveness of the consequence will be reduced. Siblings may also experience adverse feelings (e.g., resentment) if they witness their brother or sister behaving in ways that they would have been disciplined for.

Sibling socialization practices. As with typical preschool-aged sibling relationships, many parents attempt to facilitate opportunities for teaching their children how to interact with each other during play and other day-to-day activities. Stoneman and Brody (1993) included nonaversive childrearing strategies as well as assigned roles (e.g., caregiving and household duties) as positive socialization practices that parents could use for assisting these children in interacting with their brother and sisters with disabilities.

Sibling socialization goals. It was recommended that parents may assist in socializing positive sibling relationships by reflecting on their goals for socializing the relationship between their children. Factors such as age, temperament, type and severity of disability, and birth order might influence parents' desired

outcome for the sibling relationship. Stoneman and Brody (1993) commented that some parents might place more emphasis on a cooperative and supportive sibling relationship, while other parents might advocate a competitive sibling relationship. Evidently, there are differences in the importance parents place on socializing the sibling relationship, and in the amount of competition and inappropriate interactions between the siblings.

Summary

In summary, the review of the literature has provided documentation in an attempt to understand sibling relationships within the context of the family. Characteristics of the individual siblings, the effects of individual parent characteristics on parenting, the effects of family characteristics on parenting and on sibling relationships, parenting strategies, and parent-child relationships were examined as important determinants of childrens' reactions and interactions with brothers and sisters with disabilities. As a subsystem of the family unit, the direct and indirect effects that the family might have on sibling relationships was reviewed. Additional variables thought to be associated with negative psychological effects on the siblings were also reviewed. The review also focused on the additional demands that children with disabilities place on the families, and the stress imposed by these demands on the parents, and the interactions between family members.

The purpose of this research was to investigate the current needs of families with at least one child with a disability, and at least one preschool-aged child without a disability. Additionally, the unique needs and concerns of children with disabilities, and their preschool-aged siblings without disabilities were identified, as perceived by the parents. Providing parents with the opportunity to identify current needs for their family may be a good starting point for encouraging them

to access available resources for providing a nurturing and supportive environment for each family member. Additionally, identifying current needs and concerns specific to preschool-aged siblings of children with disabilities, may assist parents in accessing resources to help themselves, and their children without disabilities before greater problems evolve. The methodology used in conducting the current study will be presented in the following section.

CHAPTER 3

Method

This study was designed to investigate the needs and concerns of preschool-aged siblings of children with disabilities, as perceived by their parents. This chapter describes the participants and procedures in more detail.

Participants

The participants in this study represent a non-random sample of parents of preschoolers having brothers or sisters with disabilities. To qualify for the study, parents needed to have at least one child who attended an Early Education Program in Edmonton, Alberta, and at least one child between the ages of 2 years and 5 years 6 months without disabilities. The Early Education Program is a three-site educational program for children delayed in development between 2 years 6 months and 5 years 6 months of age. Children attending the program have a wide range of delays in development, including physical, speech-language, cognitive, and social-emotional delays. The program provides teaching based on the principles of early childhood education as well as related therapies (i.e., Physical Therapy and Speech-Language Therapy) and monthly in-home consultation (McDonald, McCarthy-Lundberg, & Tanchak, 1991).

By March 1992, all three Early Education Program Coordinators agreed to participate in the research after the purpose of the research was discussed during a telephone conversation. The Coordinators were asked to identify parents of children who currently attended one of three Early Education Programs, and had at least one child within 2 to 5 years of age without disabilities.

To ensure anonymity and confidentiality, names of potential participants were selected, and parents were notified by each Coordinator in June, 1992. At no time were names of potential participants shared with the researcher. In all instances parents completed the survey voluntarily, receiving no compensation for their participation. Potential participants received a package containing a consent form, (see Appendix A), a survey (see Appendix B), a self-addressed envelope, and a letter from the Coordinators, explaining the nature and purpose of the study, and inviting participation (see Appendix C for two sample letters).

A total of 54 packages were distributed by the Coordinators to parents qualifying for this study. Of the 54 surveys distributed, 20 surveys were returned to the researcher. Of these 20 surveys, 12 surveys were used in the study. Eight surveys were excluded from the study because the respondents did not have preschool-aged children without disabilities.

As the return rate was low (37%), a second mailing was conducted in September, 1992. At this time, each Coordinator distributed a package containing a consent form, a survey, a self-addressed envelope, and a letter from the Coordinator explaining the nature and purpose of the study and inviting participation. Also included was a follow-up letter reminding parents who received a survey in June, 1992, to return the survey at their earliest convenience (see Appendix D).

A total of 30 surveys were distributed by the Coordinators to potential participants in September. An additional 5 usable surveys were returned to the researcher, resulting in a total number of 17 usable surveys for this study.

Respondent Characteristics. As noted in the Preschool Sibling Survey (see Appendix B), the term "parent" was used to refer to all caregivers of children, including birth parents, adoptive parents, and foster parents. A total of 17

parents completed the Preschool Sibling Survey. The respondents ranged in age from 26 years to 43 years, with a mean age of 33 years. The sample consisted of 13 mothers (77%), and 4 fathers (24%). Demographic Data provided by the respondents may be found in Table 1.

Insert Table 1 about here

Spouse Characteristics. Of the 17 respondents, 13 (77%) were married, two (12%) were separated, one (6%) was divorced, and one (6%) was single. The spouses ranged in age from 27 years to 48 years, with a mean age of 36 years (see Table 1).

With respect to education background, six (36%) of the spouses were reported as having at least 12 years of education, followed by four (24 %) with less than 12 years of education, two (12%) with 3 or 4 years of University, two (12%) with more than 4 years of University, and one (6%) with technical school training (see Table 1).

Family Characteristics. With respect to family size, 13 (77%) of the families included two children, three (18%) included three children, and one (7%) included four children. Of the 17 families, one family included two children with disabilities and an older child without disabilities. The number of siblings of children with disabilities and family sizes are listed in Table 1.

The most commonly reported range for total annual family income was 32,000 - 37,000. Table 1 depicts the demographic characteristic associated with the total annual family income of those parents who responded to the survey.

Parents were requested to identify any support groups that they were members of and their total hours of involvement per week or month. With

Table 1

Descriptions of Responsdents, Spouses, and Families

	Respondent Characteristics			Spouse Characteristics		Family Characteristics		
I. D. #	Gender	Age	Educational Background	Age	Educational Background	Family Income	# of siblings	family size
1	Female	31	12 years	35	12 years	44,000 - 50,000	1	4
2	Female	36	3 or 4 years University	37	1 or 2 years College	38,000 - 43,000	2	5
3	Female	35	1 or 2 years college	34	12 years	44,000 - 50,000	1	4
4	Female	26	12 years	29	12 years	32,000 - 37,000	1	4
5	Female	26	12 years	27	< 12 years	under 20,000	1	4
6	Male	38	3 or 4 years University	38	3 or 4 years University	32,000 - 37,000	3	6
7	Female	43	12 years	43	> 4 years University	32,000 - 37,000	1	4
8	Female	36	1 or 2 years college	32	12 years	26,000 - 31,000	1	4
9	Male	35	1 or 2 years tech.training	N/A	N/A	32,000 - 37,000	1	3
10	Female	26	less than 12 years	37	< 12 years	50,000 or over	1	4
11	Male	38	12 years	40	12 years	38,000 - 43,000	2	5
12	Female	28	12 years	48	< 12 years	under 20,000	1	4
13	Female	32	1 or 2 years tech.training	30	12 years	50,000 or over	1	4
14	Female	26	12 years	27	< 12 years	32,000 - 37,000	1	4
15	Female	30	12 years	35	< 12 years	38,000 - 43,000	1	4
16	Female	34	1 or 2 years college	36	4 years College	50,000 or over	1	4
17	Male	39	> 4 years University	40	> 4 years University	50,000 or over	2	5

respect to membership in local support groups, seven (41%) respondents reported that they were members of local support groups. Of the seven respondents, six (86%) respondents were mothers and one (15%) respondent was a father. Two parents (29%) belonged to the Parents' Executive Committee, followed by one parent (14%) who belonged to the Autism Society Support Group, one parent (14%) who attended the Edmonton Down Syndrome Support Groups, one parent (14%) who belonged to the Carlisle Community League, one parent (14%) who volunteered at the Head Start Program, and one parent (14%) who belonged to the Pregnancy Council. Out of the seven respondents, one parent (14%) indicated membership in more than one local support group.

Child with a Disability Characteristics. Parents completing the survey indicated that the children with disabilities ranged in age from 2 years 9 months to 5 years 11 months, with a mean age of 4 years 9 months.

The children had a broad range of disabilities, and some parents reported more than one disabling condition (see Table 2). As this was a non-random sample, it could not be established that the breakdown represented in the following table was a representative distribution for the general population of preschoolers with disabilities.

Insert Table 2 about here

In describing their son's or daughter's disability, speech/language impairment was indicated in 29% of the cases, followed by learning disabilities (22%) and Down Syndrome (7%).

Eleven (61%) children with disabilities currently attended an Early Education Program for part of the day in a self-contained classroom, as indicated by their parents. This was followed by five (28%) children who attended an early

Table 2

Frequency and Percentage of Disabilities as Indicated by the Parents

Disabilities	Frequency	Percentage
Autism	1	2.2
Behavior Disorders	2	4.4
Cerebral Palsy	2	4.4
Down Syndrome	3	6.7
Epilepsy	1	2.2
Behavior Disorder and Epilepsy	1	2.2
Head/Spinal Cord Injury	0	0
Hearing Impairment		
- Mild	2	4.4
-Moderate	0	0
-Severe	0	0
-Profound	0	0
Visual Impairment		
- Mild	0	0
-Moderate	1	2.2
-Severe	1	2.2
-Profound	1	2.2

Disabilities	Frequency	Percentage
Mental Retardation		
-Mild	2	4.4
-Moderate	0	0
-Severe	0	0
-Profound	0	0
Speech/Language Impairment	13	28.9
Learning Disabilities	10	22.2
Other		
- Attention Deficit Disorder	1	2.2
- Developmental Delay	1	2.2
- Fetal Alcohol Syndrome	1	2.2
-Hyperactivity	1	2.2
-Autistic Characteristics	1	2.2

Education Program for part of the day, and integrated preschool or daycare program for part of the day. One child (6%) attended an Early Education Program for part of the day, and a family day home for part of the day. The remaining child (6%) attended an Early Education Program for part of the day with a home program component.

With regard to current level of independence, parents completing the survey indicated that the level of independence of their children with disabilities were as follows: six (35%) were moderately dependent, five (29%) were minimally dependent, four (24%) were completely dependent, and two (12%) were independent. The childrens' ages at diagnosis ranged from birth to 4 years 0 months, with a mean age of 1 year 4 months (see Table 3).

Insert Table 3 about here

Child without a Disability Characteristics. Respondents indicated that the ages of children without disabilities ranged in age from 1 year 0 months to 5 years 4 months, with a mean age of 2 years 6 months (see Table 3). Most of the children without disabilities were younger than their brothers and sisters with disabilities (89% of the sample).

Procedure

Administration of the survey. An appointment was set up in June, 1992, with the Coordinators to review the nature and purpose of the research. At this time, the Coordinators were asked to send potential participants a letter explaining the purpose of the research, and inviting them to participate in the study (see Appendix C). The Coordinators agreed to send out a package containing a consent form designed by the researcher (see Appendix A), a copy of the

Table 3

Descriptions of Children with Disabilities and Their Preschool-aged Siblings without Disabilities

Characteristics of Children with Disabilities				Characteristics of Preschool-Aged Siblings		
I. D. #	Age	Gender	Age at Diagnosis	Age	Gender	family size
1	5 years-6 months	male	2 years-10 months	3 years-4 months	female	4
2	5 years-6 months	male	two years-6 months	2 years 2 years	female female	5
3	3 years-8 months	female	2 weeks	2 years-1 month	female	4
4	5 years-5 months	male	3 years	3 years-4 months	female	4
5	2 years-11 months	female	Birth	4 years-1 month	male	4
6	5 years-6 months	male	2 years	3 years-1 month 3 years-1 month 1 year-3 months	female male female	6
7	4 years-6 months	female	1 day	3 years	female	4
8	3 years-6 months	male	3 years	2 years	male	4
9	4 years	male	2 years-6 months	3 years	female	3
10	4 years	male	6 months	2 years	female	4
11	4 years 3 years	male male	one year birth	5 years-4 months	female	5
12	4 years	male	birth	2 years	male	4
13	4 years	female	birth	1 year	female	4
14	4 years-6 months	male	18 months	2 years	female	4
15	6 years-3 months	male	18 months	4 years-6 months	male	4
16	4 years-11 months	female	4 months	2 years-9 months	female	4
17	5 years	male	birth	5 years 3 years	female male	5

Preschool Sibling Survey (see Appendix B), an invitation to participate in the study (see Appendix C for sample letters), and a self-addressed and stamped envelope with students of parents qualifying for the study. Potential respondents were instructed to complete and return the consent form and survey within 2 weeks of receiving the package or at their earliest convenience. The consent form explained the purpose of the research and the anticipated value to families and schools involved. The parents were informed that participation was voluntary and personal data (i.e., name of a child) were not identified in any part of the thesis. If parents chose not to participate in the study, they were asked to return the consent form and questionnaire at their earliest convenience.

At the end of the survey (see Appendix B), parents were provided with the option of participating in a follow-up telephone interview to discuss the needs and concerns of their preschool-aged children without disabilities, and the needs of their family. If interested, parents were asked to complete the consent form, and provide a phone number and convenient time to call.

Returned questionnaires were assigned a number and were referred to by that number to ensure confidentiality and anonymity. Before the data was summarized and analyzed, permission slips to participate in the follow-up interview were detached so that the researcher did not associate responses from the survey with the comments and concerns elicited during the interview. Upon completion of the study, returned surveys and information collected from the telephone interviews were destroyed.

Survey Instrument

Current literature on methods and tools of survey research indicated that surveys can be a valuable method for exploring the relationships between two or more variables (Borg & Gall, 1989). For purposes of this study, the researcher

utilized a survey instrument for standardized data collection. Information specific to personal data, current needs of families having children with disabilities and preschoolers without disabilities, current needs of children with disabilities, and current needs of preschool-aged siblings of children with disabilities were collected from parents participating in the study.

A thorough review of current research and literature on families having children with and without disabilities was conducted to investigate current social and support services and programs available to these families. In addition, time was spent discussing these issues with graduate students and professors specializing in severe disabilities, parents of children with disabilities, teenage siblings, educational consultants and teachers. This information was used to develop an exhaustive list of potential needs for the family as a unit as well as the needs of preschool-aged siblings of children with disabilities. As a result, the researcher generated a list of 84 items for a survey that were representative of the needs and concerns of families as a unit, children with disabilities, and preschool-aged siblings of children with disabilities. These items were combined with revised items from the Sibling Survey (Itzkowitz, 1989) and listed under their respective categories.

Permission to revise the types and arrangement of demographic items, and questions in the Sibling Survey was granted by Judy Itzkowitz, Ph. D., in January, 1992. The researcher discussed the purpose, rationale and significance of the study during a telephone conversation. Steps to ensure confidentiality and anonymity were also discussed. Items that were adapted from the Sibling Survey are identified in the following section.

Part I of the survey was designed to collect demographic information for each family (see Appendix B - Part I). A total of 15 demographic data items were

utilized in this study. Upon reviewing the Sibling Survey, the researcher selected and adapted three items from this survey, and created 12 items to tailor this section for use with the target group. Items that were adapted included: age of individual with a disability, identification of disability, and current program placement of the individual with a disability. Given the sample for this study, the researcher adapted the items so that parents would indicate ages and gender of each child with and without a disability in their family. Parents were also asked to indicated with a check mark which child had a disability. Second, when asked to indicate the child's disability(ies), the researcher included additional disabling conditions not included in the Sibling Survey (i.e., four levels of visual impairment, and four levels of hearing impairment). Third, the Sibling Survey asked siblings of individuals with disabilities to indicate the type of program their sibling with disabilities attended or is currently attending. For the Preschool Sibling Survey, this item was adapted so that parents could indicate the current type of Early Education Program and/or additional education programs that their children with disabilities were currently attending. Based on careful review of the literature, the following demographic data items were included in the Preschool Sibling Survey: (a) relationship to children, (b) age of respondent, (c) occupation of respondent, (d) educational background of respondent, (e) respondent's marital status, (f) age of spouse, (g)occupation of spouse, (h) educational background of spouse, (i) age and gender for each child in the family who is 5 years of age or younger, (j) child's disability(ies), (k) age at diagnosis, (l) level of independence, (m) current educational program, (n) annual family income, and (o) support group membership.

Part Two of the survey included 49 closed-form questions requiring parents to identify current needs for "information, professional support, community/generic

support, family support" (Itzkowitz, 1989, p.88). After each category, additional space was provided for parents to indicate additional needs specific to the category. The researcher included an additional category to identify current needs for strategies in managing the behavior of their children with and without disabilities, instructional strategies, how to advocate for their children with disabilities, and how to communicate effectively with family, educational professionals, and medical professionals (see Appendix B - Part 2, Category 5).

Given the nature of the study, most questions in each category of the Sibling Survey were changed. Items specific to adult siblings of brothers and sisters with disabilities were deleted. For example, the item, " To what extent do you need medical information about planning for your sibling's future and your own?" was removed. Items listed in the original survey dealing with training, were modified to deal with strategies that were specific to the potential needs of the family as a unit (Category 5: Strategies). For example, one question in the Sibling Survey asked survey participants to indicate to what extent they needed training as a sibling without disabilities in how to be more effective in managing the behavior of their siblings with disabilities. The modified survey asked a similar question, "To what extent do you need specific strategies to assist you in managing the behavior of your child(ren) with disabilities?" In the following section, items that were removed or adapted from the Sibling Survey are presented.

In Category 1: Information, the Sibling Survey included four items specific to types of information (i.e., books, audiovisual materials, television programs) about persons with disabilities. Item 1 in the Preschool Sibling Survey combined these four items, and asked parents to indicate the extent to which they needed books and materials on children with disabilities and their families. Item 10 in the Preschool Sibling Survey is the same item presented in the Sibling Survey. The

remaining 14 items were modified for the Preschool Sibling Survey.

In Category 2: Professional Support, the Sibling Survey included four items specific to respite care services, individual and family counseling, and access to services from state and local agencies. The Preschool Sibling Survey expanded on these items for a total of 11 items specific to respite care services, babysitting, support groups for the parents, educational programs, contact with educational professionals and other parents in similar situations, and special therapy services for the children with disabilities.

In Category 3: Community/Generic Support, the Sibling Survey included three items specific to transportation services and recreation programs for individuals with disabilities, and contact with other siblings of individuals with disabilities. In the Preschool Sibling Survey, the same items were re-worded to include both children with disabilities and their preschool-aged siblings without disabilities. In addition, items specific to contact with medical professionals, other parents in similar situations, and clergy were added to this section.

In Category 4: Family Support, the Sibling Survey included three items specific to personal support from family, solitary time with parents, and participation in activities with parents. In the Preschool Sibling Survey, the same items were revised to include both children with disabilities and their preschool-aged siblings without disabilities, spouses, extended family members, and friends. Additional items were added to address time needed alone, and the extent to which parents needed to assist family members discuss problems during difficult times.

Category 5: Strategies, included six items specific to parents' potential need for strategies regarding well-being, communication with educational professionals, family and friends, positive child-rearing strategies, advocacy

issues, and teaching their children with disabilities. The Sibling Survey listed nine items specific to training siblings of individuals with disabilities in the following areas: (a) advocate for sibling with disability, (b) behavior management, (c) personal wellness, (c) time management, and (e) communication strategies. For purposes of the Preschool Sibling Survey, items in the Sibling Survey were adapted so that they were more specific to families having children with disabilities, and preschool-aged children without disabilities. One item, "To what extent do you need strategies to help you reduce and cope with stress and anxiety?" was unchanged.

For ease of scoring and interpretation, the 5 - point Likert scale (i.e., 1=no need, 2=low, 3=moderate, 4=high, 5=very high) used in the original Sibling Survey was retained. Additional space was provided for parents to include information specific to their needs and concerns within each category.

Part three of the survey, assessed the unique needs and concerns of children with disabilities, and preschool-aged siblings of children with disabilities that were not addressed in the Sibling Survey. Seven closed and open-form questions were designed to identify current needs of preschoolers with disabilities (see Appendix B - Part 3, Category 6). Subsequently, twelve closed and open-form questions were designed to represent potential areas of current need and concern as discussed in the current literature: (a) sibling support services, (b) caregiving responsibilities, (c) extra-curricular participation, (d) peers apart from brothers or sisters, (e) self-esteem, and (f) level of independence (see Appendix B - Part 3, Category 7). A 5 - point Likert Scale (i.e., 1 = never, 2=seldom, 3=somewhat, 4=usually, 5=always) was utilized for this section of the survey. In addition, ample space was provided below each question for participants to make comments and/or concerns regarding the current item (See Appendix B - Part 3, Categories 6 and 7)).

Validity. For purposes of this study, face validity was determined by examining the items and judging if they appeared to represent the content. To determine face validity, a group of judges consisting of two parents having preschoolers with and without disabilities, two graduate students, and one University professor specializing in severe disabilities were asked the following question, "In your judgment, do the items in the survey look like they measure the content they are supposed to? If so, you would say the survey has face validity." The judges were also asked to indicate whether the items were appropriate for that particular category. On the basis of this feedback, minimal alterations were made to this survey (i.e., spelling corrections, additional space was provided at the end of each category for comments, clarification of instructions before parts two and three of the survey, and clarification of item 14 in demographic information). Each judge indicated that each of the 84 items measured the content they were supposed to in each of their respective categories. Three categories (i.e., Category 1: Information, Category 2: Professional Support, and Category 5: Strategies) were refined based on the judges' feedback and included in the final version of the survey.

Five parents with preschoolers having siblings with disabilities, and educational professionals working in the area of special education, were asked to participate in a pilot testing of the surveys in June, 1992. Participants were instructed to carefully examine the survey and provide comments, concerns and suggestions regarding the number and types of questions and demographic data required from parents. Also, the researcher was interested in collecting useful information regarding the length of the surveys, time to complete the survey, and designated categories. Feedback from parents was positive and minimal corrections were made to the survey (i.e., wording of some items, spacing

between items, and length of instructions before parts 2 and 3 of the survey). Based on these comments, the researcher altered the wording for some items, provided more space between the items, and enlarged the font. In addition, minimal adjustments were made to clarify instructions.

Follow-up telephone interview. Once the survey data were summarized, the researcher conducted a follow-up telephone interview with parents who completed the telephone consent form at the end of the survey.

The interview was designed to discuss parents' general concerns of their preschool-aged children without disabilities, and the needs of their family in more detail. Closed and open-ended questions were developed by the researcher and based on a review of current literature pertaining to families having children with disabilities, and the needs of preschoolers having brothers or sisters with disabilities (see Appendix E). Additionally, the researcher was interested in suggestions regarding the survey as an effective tool for assessing the needs and concerns of preschoolers having siblings with disabilities. The parents were reminded about steps taken to ensure confidentiality and anonymity.

Responses to closed and open-form questions, as well as comments, suggestions, and/or recommendations were recorded by the researcher on the telephone interview form (see Appendix E). These comments provided an additional descriptive measure of the needs and concerns of preschool-aged siblings of children with disabilities, the needs of the family, as well as a qualitative measure of the efficacy of the Preschool Sibling Survey as an assessment tool.

Data Analysis

Since the study was descriptive, the data analyses largely consisted of descriptive techniques. For example, demographic information and results from the closed-form questions were summarized in terms of frequencies and percentages. Subsequently, responses for each item were described quantitatively using measures of central tendency such as the mean and mode, and measure of variability such as standard deviation for each item in the survey. Additional comments and/or concerns provided by the items, and in the space provided at the end of each category were included with descriptive information provided for each survey item.

Information collected during the telephone interview were summarized in terms of percentages. For each closed-ended question, the percentage of parents who agreed with the statement, and the percentage of parents who disagreed with the statement were presented. Then, parents were asked to provide any comments, suggestions, and/or recommendations they might have regarding the previous statements. All comments, suggestions, and/or recommendations were presented after each closed-ended question, as provided by the parents.

Summary

In summary, this chapter presented a description of the participants, spouses, children with disabilities, preschool-aged siblings of children with disabilities, and families. Procedures utilized by the researcher were presented. More specifically, administration procedures for the Preschool Sibling Survey, and the follow-up telephone interview were outlined. The development of the survey and telephone interview were presented, and a brief description of procedures used to summarize and describe the results followed. The following chapter will present the results of the research.

CHAPTER 4

Results

Two primary research questions were asked in this study. The first question was; What are parents' perceptions of the needs and concerns of their family when one of their children has a disability? Part 2 of the Preschool Sibling Survey included 49 closed-form questions asking parents to identify current family needs in each of the following categories: (a) information, (b) professional support, (c) community/generic support, (d) family support, and (e) strategies. For ease of scoring and interpretation, a 5 - point Likert scale was utilized for each item (1=no need, 2=low, 3=moderate, 4=high, 5=very high).

The second question was; What are parents' perceptions of the needs and concerns of their children with disabilities, and their preschool-aged siblings without disabilities? Two subsequent categories in Part 3 of the survey included 19 closed-form questions specific to the unique needs and concerns of preschool-aged siblings without disabilities and their brothers or sisters with disabilities. For ease of scoring and interpretation, a 5 - point Likert scale was utilized for each item (1=never, 2=seldom, 3=somewhat, 4=usually, 5=always).

A telephone interview was also used to discuss parents' general concerns of preschool-aged siblings of children with disabilities, and the needs of their family in more detail. A total of eight closed-ended and eight open-ended questions specific to the unique needs and concerns of preschool-aged siblings of children with disabilities, and families having children with disabilities and preschool-aged children without disabilities were designed by the researcher. Once the telephone interviews were completed, information collected for the closed-ended questions

were summarized and described in terms of group responses (i.e., percentages) to each of the questions. Comments, concerns, and/or recommendations provided by the parents for the open-ended questions were then presented after each closed-ended question.

The results are presented in two major sections. First, Research Question 1 is presented, followed by the survey results (i.e., Part 2: Categories 1 to 5) and follow-up telephone interview results (i.e., Items 1 to 8) pertaining to this question. Then, Research Question 2 is presented, followed by the survey results (i.e., Part 3: Categories 6 and 7) and follow-up telephone interview results (i.e., Items 9 to 16) pertaining to this question. Comments regarding the Preschool Sibling Survey and Telephone Interview as effective tools for ascertaining the needs of families having children with and without disabilities, the needs of the children with disabilities, and the needs of their siblings without disabilities, as indicated by the parents, are included at the end of the chapter.

Research Question 1

What are parents' perceptions of the needs and concerns of families having children with disabilities and preschool-aged children without disabilities as identified during the survey, and during the telephone interview?

Survey Results: Part 2 - Categories 1 to 5

Part 2 of the Preschool Sibling Survey addressed potential needs and concerns for families having children with disabilities, and preschool-aged children without disabilities in five different categories. The results from each category are presented in the following section. First, the researcher defines the category and describes the types of items adapted from the Sibling Survey (Itzkowitz, 1989), as well as items designed by the researcher for that category. Then, the information collected from Part 2 of the Preschool Sibling Survey are

summarized in terms of group responses to each of the questions. The researcher statistically describes each survey item using measures of central tendency (i.e., mean and mode), and measures of variability (i.e., standard deviation). Tables 4 to 8 present each of the items with the corresponding mean, mode, and standard deviation for each item. Following this section, the researcher presents each item with a statement specific to the number of respondents who responded to each item in parentheses. Group responses and comments provided by respondents to each item follow.

Category 1 - Information

"Information" was defined as the access to printed materials, audiovisual materials, and parent sessions with information specific to disabilities, child development, community resources and services, and educational programming for families having children with disabilities. A total of 14 questions, adapted from the Sibling Survey (Itzkowitz, 1989) comprised Category 1 - Information. Three questions addressed child development, one addressed parenting skills, four addressed community programs and support services, two addressed accessibility to financial resources, one addressed accessibility to information for siblings of children with disabilities, one addressed educational programming, and two addressed medical information services. Most of the respondents, sixteen parents (94%), reported on each item. Utilizing a Likert scale, the range of possible scores was 14 to 70. Overall , parents indicated a moderate level of need as indicated by their scores. Parents' scores ranged from a mean of 2.41 (on information for accessing babysitting services) to a mean of 4.53 (on information for accessing future school placements). For most items, the mode was 1.00 (i.e., no need) with two items having modes of 5.00 (i.e., very high level of need for information on accessing future school placements and information

for accessing specialized therapy services). A summary of the results may be found in Table 4.

Insert Table 4 about here

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1. Books and materials (16/17). Almost half of the parents (41%) indicated a low level of need for books and materials on children with disabilities and their families, followed by five parents (29%) who felt a high need, and two parents (12%) who indicated a moderate level of need for this information. One parent (6%) indicated a very high need, and another parent (6%) indicated no need for books and materials. The remaining parent (6%) indicated that she was not interested in receiving this type of information.

2. Managing childrens' behaviors (16/17). Five respondents (29%) indicated a moderate level of need for information on how to handle their childrens' behaviors. This was followed by a very high level of need indicated by four parents (24%), a high level of need indicated by three parents (18%), and a low level of need indicated by another three parents (18%). Parents who indicated a very high level of need had no demographic data in common; however, parents commented that it was difficult to access this information. Interestingly, one parent who expressed a very high level of need, commented that there was no information specific to managing the behaviors of children who were born premature and blind. One parent (6%) expressed no need for this information, and one parent (6%) did not respond to this item.

3. Playing with children (16/17). Less than one quarter of the parents (24%) indicated a moderate level of need for information specific to playing or talking with their children, followed by four parents (24%) who indicated no need for this

Table 4

Preschool Sibling Survey Descriptive Statistics: Category 1 - Information

Item Description	Mean	Mode	Standard Deviation
1. Books and materials	3.12	2.00	1.67
2. Managing behaviors	3.65	3.00	1.66
3. Playing and talking with children	3.06	1.00	1.85
4. Growth and development of children	2.65	1.00	1.77
5. Access financial services	3.06	1.00	1.85
6. Community resources and services for siblings	3.29	3.00	1.83
7. Community programs and services for families	2.88	2.00	2.00
8. Access respite care	2.65	1.00	1.00
9. Access babysitting services	2.41	1.00	1.00
10. General information about siblings	3.35	3.00	3.00
11. Future school placements	4.53	5.00	0.72
12. Medical condition, equipment and supplies	2.53	1.00	1.84
13. Access specialized therapy services	3.65	5.00	1.22
14. Parent support groups	2.53	1.00	1.84

type of information. Another three parents (18%) felt there was low need, and three more parents (18%) indicated a high level of need for this type of information. One of the parents who expressed a high level of need mentioned that she and her spouse were unable to find information specific to parents playing with their children born premature and blind. Only two parents (12%) expressed a very high level of need for this type of information, and one parent (6%) did not respond to this item.

4. Growth and development of children (16/17). Five parents (29%) indicated no need for information on the growth and development of children, followed by four parents (24%) who indicated a low level of need, and four parents (24%) who indicated a moderate level of need. Three parents (18%) indicated a high level of need and commented that it was difficult for parents to access information specific to child development. More specifically, one parent expressed that she and her spouse were unable to access information available to her and her spouse on the growth and development of children who were born premature and with a progressive vision loss. One parent (6%) did not respond to this item.

5. Access to financial services (16/17). Less than one quarter of the parents (24%) indicated a moderate level of need on information specific to accessing financial resources available to families having children with disabilities. It is interesting to note that two parents (12%) who expressed a very high level of need for this information, also indicated that their total annual income for their households was under 20,000. One family had a child with disabilities and one preschooler without disabilities. The parent indicated that the child with disabilities was minimally dependent. The other family had two children with disabilities and one preschooler without disabilities. Both children with disabilities

were rated as moderately dependent. Three families (18%) expressed a high level of need. Although there were differences with respect to total annual income for these three households, the number of children with disabilities, and their childrens' current level of independence, all three families commented that they were unable to access this type of information. Three parents (18%) indicated a low level of need, and commented that they currently had access to this information, while the remaining four parents (24%) indicated no need for this information. It is interesting to note that the total annual income for their households, the number of children with disabilities, and their childrens' current level of independence varied. One parent (6%) did not respond to this item.

6. Community resources and services for siblings (16/17). Four parents (24%) indicated a moderate level of need for information specific to community resources and services for siblings. This was followed by three parents (18%) who indicated a low level of need , three parents (18%) who indicated no need for this information, three parents (18%) who indicated a high level of need , and three more parents (18%) who indicated a very high level of need for this type of information. Both parents expressing a very high level of need indicated that they had preschoolers who were younger than their children with disabilities. In addition, one of the families commented that they were aware of no programs for siblings of children with disabilities in Edmonton. One parent (6%) did not respond to this item.

7. Community programs and services for families (16/17). Almost half of the parents (41%), indicated a low level of need for information about community programs and services available for the family. Another three parents (18%) expressed no need for this information. It is interesting to note that two of the three families had children with similar disabilities (i.e., speech delayed and

learning disabilities), both families had total annual incomes between 32,000 - 37,000, and both respondents had similar educational backgrounds (i.e., 3 or 4 years of University). Two parents (12%) indicated a moderate level of need, two parents (12%) indicated a high level of need, and two parents (12%) indicated a very high level of need for this information. Parents indicating a very high need for this information had no demographic data in common. One parent (6%) did not respond to this item.

8. Respite care services (16/17). Fewer than one third of the parents (29%) expressed no need for information specific to accessing respite care services. One of these parents commented that she and her spouse had this information. Five parents (29%) indicated a moderate level of need, followed by four parents (24%) who indicated a low level of need for this information, and one parent (6%) who expressed a high level of need. One parent (6%) who expressed a very high level of need for this information indicated that she was a single parent and currently not working outside of the home. Additionally, this parent indicated that she was an active participant in four parent support groups. One parent (6%) did not respond to this item.

9. Babysitting services (16/17). Over half of the parents (53%) indicated they had no need for information specific to accessing babysitting services. Two parents (12%) indicated a low level of need, and another two parents (12%), indicated a moderate level of need for this information. The parents who expressed a low level of need indicated that they had information on how they could access babysitting services for their children with disabilities; however, they did not utilize babysitting services very often. One parent (6%) indicated a high level of need, and two parents (12%) indicated a very high level of need for this information. One of the parents expressing a very high level of need emphasized

that she had no access to this type of information. It is interesting to note that this parent also indicated a very high level of need to items 5, 6, 7, and 8 in Category 1 - Information. One parent (6%) did not respond to this item.

10. General information about siblings (16/17). Less than half of the parents (35%) expressed a moderate level of need for general information about siblings of children with disabilities. Five parents (29%) indicated a high level of need for this information, two parents (12%) indicated a low level of need, and two parents (12%) indicated no need for this type of information. One parent, who indicated no need, commented that she had access to materials and workshops for siblings of children with disabilities; however, her child without disabilities was too young to participate in these programs. One parent who indicated a high level of need, expressed that he did not know how to access this information. An additional parent (6%) who indicated a very high level of need for this information commented that she was very interested in accessing more information specific to sibling workshops and reading materials for her child without disabilities. This same parent expressed a very high level of need for item 6 - community resources and services for siblings. It is interesting to note that this parent was married and worked outside of the home. The child with disabilities was minimally dependent and had a younger sibling without disabilities. The total annual income was 44,000 - 50,000 and both parents participated in a parents executive committee for 2 to 3 hours per month. One parent (6%) did not respond to this item.

11. Future school placements (17/17). Over half of the parents (65%) indicated a very high level of need for information about future school placements for their children with disabilities. Four parents (24%) indicated a high level of need, and two parents (12%) indicated a low level of need for this information.

12. Medical condition, equipment, and supplies (16/17). Less than half of the parents (35%) expressed no need for information concerning their childrens' medical condition, medical equipment, and medical supplies. One of these parents commented that she knew how to access this type of information. Another parent expressing no need commented that she was not interested in this type of information. Four parents (24%) indicated a low level of need, and four parents (24%) indicated a moderate level of need for this information. One parent who expressed a moderate level of need indicated that she would like information specific to children who have lung damage. One parent (6%) expressed a high level of need, and one parent (6%) expressed a very high level of need for this information. This parent indicated that as a single parent, she found it difficult to access the latest information on her child's condition, particularly information specific to hyperactivity, behavior disorders, and learning disabilities. One parents (6%) did not respond to this item.

13. Specialized therapy services (17/17). Six parents (35%) indicated a very high level of need for information specific to accessing specialized therapy services for their children with disabilities. Six of the seven parents described their children with disabilities as having a speech/language impairment and learning disabilities. One child had a mild hearing impairment, epilepsy speech/language impairment, and learning disabilities. The remaining children had moderate visual impairments in addition to speech/language impairments and learning disabilities. Four parents (24%) indicated a moderate level of need, and four parents (24%) indicated a low level of need for this information. Two parents who expressed a low level of need commented that they already knew how to access this information. The remaining three parents (18%) indicated a high level of need for this information. One of these three parents described her

child with disabilities as having a speech/language impairment. Another parent described her child with disabilities as displaying autistic characteristics and having a speech/language impairment. Finally, the third parent described her child as having epilepsy, behavior disorders, mild mental retardation, learning disabilities, speech language impairment, and Attention Deficit Disorder.

14. Parent support groups (16/17). Less than half of the parents (35%) felt there was no need for information on support groups for parents. One of these parents commented that she knew how to access this information and indicated that she attended the Edmonton Down Syndrome Family Support Group. One parent indicated that she was not interested, and the remaining four parents indicated that they did not belong to any family and/or parent support groups. Four parents (24%) indicated a low level of need, followed by four parents (24%) who indicated a moderate level of need, and one parent (6%) who indicated a high level of need for this type of information. All of these parents identified at least one family and/or parent support group that they currently attended. One parent (6%) expressed a very high level of need for this information, and commented that she needed a support group for mothers who were single parents. Additionally, she commented that single parents are solely responsible for their childrens' development as well as for finding proper care and programs for them. The parent indicated that she belonged to a pregnancy counseling group, the parent's executive committee, and contributed 16 hours per month of volunteer service to the Headstart Program. One parent (6%) did not respond to this item.

Category 2 - Professional Support

In this study, "professional support" was defined as medical, social, personal and/or recreational support services available to families having children with

disabilities. These services would be provided by medical, educational, and/or other human service professionals. A total of 11 questions comprised Category 2 -Professional Support. Out of 11 questions, two questions addressed provision of respite care and babysitting services, two addressed availability of parent support groups and professional services, two addressed education programs, two addressed counseling and availability of school workshops for parents, and three addressed opportunities to talk with educational professionals, medical professionals, and with parents having children with similar needs.

Sixteen of the 17 respondents reported on each item, and the range of possible scores was 11 to 55. Parents' scores ranged from a mean of 2.35 (more contact with In-Home Consultants) to a mean of 4.12 (availability of professional services for children with disabilities). Five questions had a mode of 1.00 (i.e., no need), and 1 question had a mode of 5.00 (i.e., very high level of need for education programming for children with disabilities). A summary of the results may be found in Table 5.

Insert Table 5 about here

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1. Provision of respite care services (15/17). Five parents (29%) indicated they had a low level of need for provision of respite care services. Three parents (18%) indicated a moderate level of need, followed by three parents (18%) indicated no need, and two families (12%) who indicated a high level of need for this type of information. Two parents (12%) indicated a very high level of need for this information, and two parents (12%) did not respond to this item.

2. Provision of babysitting services (16/17). Four parents (24%) indicated that they had no need for provision of babysitting services to their families. These

Table 5

Preschool Sibling Survey Descriptive Statistics: Category 2 - Professional Support

Item Description	Mean	Mode	Standard Deviation
1. Provision of respite care services	3.29	2.00	2.17
2. Provision of babysitting services	3.06	1.00	1.92
3. Availability of parent support groups	2.65	1.00	1.80
4. Availability of professional services	4.12	3.00	1.27
5. Education programs for child with disabilities	4.06	5.00	2.22
6. Education Program for child without disabilities	3.24	1.00	2.41
7. Counseling for the family	2.53	1.00	2.40
8. Availability of school workshops/sessions for parents	3.47	3.00	2.15
9. More contact with In-Home consultants	2.35	2.00	1.69
10. More time to talk with teachers	2.88	3.00	1.54
11. More time to talk with parents	2.77	1.00	1.82

respondents (i.e., mothers) had spouses who were currently employed. Additionally, all four mothers had at least 12 years of education. Each family had preschoolers who were younger than their brothers or sisters with disabilities. One family had three preschoolers without disabilities, and an older boy with a speech/language impairment. This parent commented that her family participated in activities as a family. Four parents (24%) felt a low level of need, three parents (18%) expressed a moderate level of need, followed by three parents (18%) who indicated a very high level of need for this service. Two parents (12%) expressed a high level of need, and one parent (6%) who did not respond to this item, commented that she was not interested in accessing babysitting services.

3. Availability of parent support groups (16/17). Out of 16 respondents, one parent (6%) indicated a very high level of need for parent support groups and services from provincial and local agencies. The same parent indicated that she regularly attended two parent support groups. One parent (6%) who expressed a high need for this type of service did not provide any comments with her rating. Five parents (30%) indicated a moderate level of need, and four parents (24%) indicated a low level of need for this type of service. One parent who indicated a low level of need commented that she already participated in one family support group for 5 hours per month. Five parents (30%) expressed no need for this type of service, and each of these parents did not specify any family support groups to which they currently belonged. The remaining parent (6%) did not respond to this item.

4. Availability of professional services (16/17). Less than half of the parents (35%) indicated a moderate level of need for professional services for their children with disabilities (e.g., speech therapy). Another six parents (35%)

indicated a high level of need, followed by four parents (24%) who expressed a very high level of need for these services. Two parents who expressed a high level of need and two parents who expressed a very high need, commented that they needed professional services specific to speech therapy. One parent (6%) did not respond to this item.

5. Education programs for child with disabilities (15/17). Almost half of the parents (47%) indicated a very high level of need for a daycare program or preschool program for their children with disabilities. Each of the eight parents indicated their children with disabilities currently attended an Early Education Program for part of the day in a self-contained classroom. None of the parents provided additional information regarding school and/or community programs that their children may have attended for the other part of the day. Four parents (24%) indicated no need for this type of program. Of these four parents, one parent sent her child to an Early Education Program for part of the day and an integrated preschool or daycare program for part of the day. The remaining three parents sent their children to an Early Education Program for part of the day in a self-contained classroom. No information was provided about additional programs for these children for the other part of the day. The remaining three parents (18%) expressed a moderate level of need for this type of program. Children in these families attended an Early Education Program for part of the day in a self-contained classroom with no additional programming for the other part of the day. Two parents (12%) did not respond to this item.

6. Education program for child without disabilities (15/17). Almost half of the parents (41%) expressed no need for a day care program for their children without disabilities. Four parents (24%) indicated a very high level of need, and four parents (24%) indicated a moderate level of need for this type of program.

Two parents who indicated a moderate level of need commented that they preferred to have their children with and without disabilities in the same preschool program. The remaining two parents (12%) did not respond to this item.

7. Counseling for the family (15/17). Over half of the parents (59%) indicated that they had no need for counseling for their families. Two parents (12%) indicated a moderate level of need, one parent (6%) expressed a low level of need, and one parent (6%) expressed a high level of need. None of these parents provided additional comments specific to counseling for their families. The remaining parent (6%) indicated very high level of need for counseling. This parent commented that she and her husband needed more time to talk with each other and more sleep. Both parents worked outside of the home and their total annual income was 50,000 or over. Their child with disabilities was tentatively diagnosed with developmental delay and speech/language impairment; although, this child is minimally dependent, the parent indicated that the child is still in diapers all the time and displays inappropriate self-stimulating behaviors to express her needs and wants. The remaining two parents (12%) did not respond to this item.

8. Availability of school workshops/sessions for parents (15/17). Five parents (29%) indicated a moderate level of need for school workshops and/or information sessions for parents of children with disabilities. Three parents (18%) indicated no need, three parents (18%) indicated a low level of need, and three parents (18%) indicated a very high level of need for this type of service. One parent (6%) indicated a very high level of need for this type of service. None of the parents provided comments specific to this item; however, three of the five parents who indicated a very high level of need also expressed a very high level of need for information about community resources and services for their children

with disabilities and their preschool-aged children without disabilities. Two parents (12%) did not respond to this item.

9. More contact with home consultants (16/17). Almost half of the parents (41%) indicated a low level of need for more contact with the In-Home Consultants to discuss concerns regarding their children with disabilities and their preschool-aged children without disabilities. This was followed by no need as indicated by four parents (29%), a moderate level of need as indicated by three parents (18%), and a very high level of need as indicated by one parent (6%) The parent expressing a very high level of need for this service placed a star by the rating (i.e., 5**). One parent (6%) did not respond to this item.

10. More time to talk with teachers (16/17). Over half of the parents (53%) indicated a moderate level of need for more time to talk with the teachers of their children with disabilities. This was followed by a low level of need indicated by four parents (24%), no need indicated by two parents (12%), and a high need for this service, as indicated by one parent (6%). None of these parents provided comments specific to this item. One parent (6%) did not respond to this item.

11. More time to talk with parents (16/17). Five of the parents (29%) indicated no need for more time to talk with other parents who had children like theirs. Another five parents (29%) indicated a moderate level of need for this service, followed by three parents (18%) who indicated a low level of need, and two parents (12%) who indicated a high level of need . One parent (6%) expressed a very high level of need, and commented that she was single parent who wanted to speak with mothers who were in similar situations. One parent (6%) did not respond to this item.

Category 3 - Community/Generic Support

"Community/generic support" was defined as access to personal support from

other families having children with disabilities and preschool-aged siblings without disabilities, medical professionals, human service professionals, clergy, as well as access to community recreational programs and transportation services. Out of eight questions, two questions addressed availability of transportation services, two addressed availability of recreational programs, one question addressed

assistance needed in locating medical professionals, two questions addressed assistance needed in locating parents and/or clergy for support. The range of possible scores was 9 to 45, and all of the respondents indicated the extent to which they needed each of the listed items in this category.

Parents' scores ranged from a mean of 1.41 (meet with a Minister, Priest, or Rabbi) to a mean of 3.41 (availability of recreational programs for children with disabilities). There were 4 questions with a mode of 1.00 (i.e., no need) and 1 question with a mode of 5.00 (i.e., a very high level of need for availability of recreational programs for children with disabilities). A summary of the results may be found in Table 6.

Insert Table 6 about here

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1. Transportation services for children with disabilities (17/17). Less than half of the parents (35%) indicated that they had no need to access transportation services for assisting their children with disabilities access to community activities. Five parents (29%) expressed a moderate need, followed by a low level of need indicated by three parents (18%), a high level of need indicated by two parents (12%), and a very high level of need indicated by one parent (6%). Parents who expressed high or very high levels of need for this service, also indicated that both parents were employed outside of the home. One family

Table 6

Preschool Sibling Survey Descriptive Statistics: Category 3 - Community/Generic Support

Item Description	Mean	Mode	Standard Deviation
1. Availability of transportation services for child with disabilities	2.35	1.00	1.27
2. Availability of transportation services for child without disabilities	1.77	1.00	0.97
3. Contact with other parents	2.41	2.00	1.06
4. Availability of recreational programs for child with disabilities	3.41	5.00	1.33
5. Availability of recreational programs for child without disabilities	2.82	3.00	1.43
6. Assistance in locating a doctor	1.94	1.00	1.30
7. Meet and talk with parents	2.53	2.00	1.33
8. Meet with Minister, Priest, or Rabbi	1.41	1.00	1.06

in particular, indicated that both parents were physicians and commented that their schedules did not permit them to drive their child with disabilities to community-based activities during the day and/or after school. Consequently, they needed assistance in accessing this type of service for their child.

2. Transportation services for children without disabilities (17/17). Over half of the parents (53%) indicated no need for accessing transportation services for assisting their children without disabilities access to community activities. Four parents (24%) expressed a low level of need, followed by three parents (18%) who indicated a moderate level of need, and one parent (6%) who indicated a high level of need for this type of service. The parent who expressed a high level of need indicated that both parents were currently working outside of the home and commented that one of their children without disabilities was too young (i.e., 18 months) to participate in community-based activities. Another child without disabilities was 2 years old and could attend community programs; however, it was difficult to access this type of service when both parents were working.

3. Contact with other parents (17/17). Less than one third of the parents (29%) expressed a moderate level of need for contact with other parents and siblings of children with disabilities. Another five parents (29%) indicated a low level of need, followed by four parents (24%) who indicated no need for this type of contact. The remaining three parents (18%) who expressed a high level of need, also indicated a high level of need for community resources and services available to their preschoolers without disabilities, and a high level of need for general information about siblings of children with disabilities. Although some parents indicated a low level or no need for this type of contact, some of these parents expressed a high need for community resources, services, and general information about siblings of children with disabilities.

4. Recreational programs for children with disabilities (17/17). Five parents (30%) expressed a very high level of need for recreational programs for their children with disabilities. Four parents (24%) indicated a moderate level of need, and four parents (24%) indicated a low level of need. Three additional parents (18%) indicated a high level of need. The parent who expressed a low of need for these programs commented that she did not require these programs for either child. Four of the eight parents who expressed a high or very high level of need for these programs, indicated a low level of need or no need for these programs for their preschoolers without disabilities. One parent (6%) did not respond to this item.

5. Recreational programs for children without disabilities (17/17). Five parents (30%) expressed a moderate level of need for recreational programs for their children without disabilities, and four parents (24%) who expressed no need for these programs. This was followed by three parents (18%) who expressed a very high level of need, three parents (18%) who expressed a low level of need, and two parents (12%) who expressed a high level of need. Four parents who expressed a high level and very high level of need for these programs, also indicated a high and very high level of need for recreational programs for their preschoolers with disabilities.

6. Assistance in locating a doctor (17/17). More than half of the parents (53%) indicated that they had no need for assistance in locating a doctor who understood their needs and the needs of their children with disabilities. Four parents (24%) indicated a low level of need for this assistance, followed by a high level of need indicated by two parents (12%), a very high level of need indicated by one parent (6%), and a moderate level of need indicated by one parent (6%). None of the parents provided additional comments for this item.

7. Meet and talk with parents (17/17). Less than half of the parents (35%) indicated a low level of need for meeting and talking with other parents who have children like theirs. Four parents (24%) expressed no need, three parents (18%) expressed a moderate level of need, two parents (12%) indicated a high level of need, and two parents (12%) indicated a very high level of need for this type of support.

8. Meet with minister, priest, or rabbi (17/17). Over half of the parents (82%) indicated no need for meeting with a minister, priest, or rabbi. This was followed by one parent (6%) who indicated a very high level of need, a moderate level of need indicated by one parent (6%), and a low level of need indicated by one parent (6%).

Category 4 - Family Support.

"Family Support" was defined as the availability of personal support from spouses, extended family members and personal friends. In addition, the quantity and quality of interactions between the respondents and their immediate family members (i.e., children with and without disabilities and spouses) were included within this category. Out of a possible nine questions, four questions addressed the need for more quality time with immediate family members, four addressed the need for more support from family members and friends, and one addressed the need for more solitary time. The range of possible scores was 9 to 45.

Parents' scores ranged from a mean of 2.71 (emotional support from friends) to a mean of 3.82 (more time for myself). Three questions had a mode of 1.00 (i.e., no need), and 2 questions had a mode of 5.00 (i.e., a very high level of need for more quality time with the child with disabilities, and more time for myself). Parents reported a moderate level of need for item 1 - "To what extent do you

need more quality time with your child without disabilities?". The mean score for this item was 3.12, and the mode was 3.00. A summary of the results may be found in Table 7.

Insert Table 7 about here

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1. More quality time with children without disabilities (17/17). Five parents (29%) expressed a moderate level of need for more quality time with their children without disabilities. Four parents (24%) expressed a very high level of need, and another four parents (24%) expressed no level of need for this type of family support. This was followed by a high level need indicated by three parents (18%), and a low level of need indicated by one parent (6%) for this type of support.

2. More quality time with children with disabilities (17/17). Less than half of the parents (35%) indicated a very high level of need for more quality time with their children with disabilities. This was followed by a moderate level of need indicated by four parents (24%), a high level of need indicated by three parents(18%), no need indicated by three parents (18%), and a low level of need indicated by one parent (6%) for this type of family support. Sixteen out of 17 parents gave the same ratings for more quality time with each child in their family. For example, one parent who indicated a very high level of need for more quality time with her child without disabilities, also indicated a very high level of need for more quality time with her child with disabilities.

3. More quality time with spouse (15/17). Five parents (29%) indicated a very high level of need for more quality time with their spouses. One of these parents commented that she lost two spouses because of the difficulty in dealing

Table 7

Preschool Sibling Survey Descriptive Statistics: Category 4 - Family Support

Item Description	Mean	Mode	Standard Deviation
1. More quality time with child without disabilities	3.12	3.00	1.50
2. More quality time with child with disabilities	3.47	5.00	1.51
3. More quality time with spouse	3.77	3.00	2.02
4. Time to discuss problems with spouse	3.77	3.00	2.02
5. More support from spouse during difficult times	3.24	1.00	2.33
6. Emotional support from extended family members	2.71	1.00	1.36
7. Emotional support from friends	2.65	1.00	1.46
8. More time for myself	3.82	5.00	1.29
9. Help family discuss problems and support	3.24	2.00	1.86

with two children with disabilities. Another four parents (24%) indicated a high level of need for this family support. This was followed by a moderate level of need indicated by three parents (18%), no need indicated by two parents (12%), and a low level of need indicated by one parent (6%) for this type of family support. The remaining two parents (12%) commented that the item was not applicable to them.

4. Time to discuss problems with spouse (15/17). Less than one third of the parents (29%) indicated a moderate level of need for more time to discuss problems with their spouses. Three parents (18%) indicated a high level of need, and another three parents (18%) indicated a very high level of need for this type of family support. This was followed by a low level of need as indicated by two parents (12%), and no need for this type of family support as indicated by two parents (12%) The two remaining parents (12%) indicated that the question was not applicable to them.

5. More support from my spouse during difficult times (15/17). Five parents (29%) expressed no need, and four parents (24%) expressed a low level level of need for more support from their spouses during difficult times. This was followed by a very high level of need as indicated by three parents (18%), a high level of need as indicated by two parents (12%), and a moderate level of need as indicated by one parent (6%). Two parents (12%) indicated that the question was not applicable to them.

6. Emotional support from extended family members (17/17). Three parents (24%) indicated no need for emotional support from extended family members. Three parents (24%) indicated a low level of need, three parents (24%) indicated a moderate need, followed by a high level of need for this type of support as indicated by three parents (18%). Two parents (12%) who expressed a very high level of need, also indicated that they were single parents.

7. Emotional support from friends (17/17). Five parents (29%) indicated no need for emotional support from friends. Another five parents (29%) indicated a moderate level of need. This was followed by three parents (18%) who expressed a very high level of need, and three parents who expressed a low level of need (18%). The remaining parent (6%) expressed a high level of need for emotional support from friends.

8. More time for myself (17/17). Almost half of the parents (41%) expressed a very high need for more time for themselves. One parent commented that she needed more sleep. Four parents (24%) indicated a high level of need, followed by a moderate level of need as indicated by three parents (18%), and a low level of need as indicated by another three parents (12%). One parent (6%) indicated no need for more time for herself.

9. Help family discuss problems and provide support (16/17). Six parents (35%) indicated a low level of need to help their families discuss problems and support each other during difficult times. Four parents (24%) expressed a very high level of need, followed by a moderate level of need as indicated by three parents (18%), no need as indicated by two parents (12%), and a high level of need as indicated by one parent (6%). Parents who expressed a very high level of need for this item, also indicated a very high level of need for more time for themselves. One parent (6%) indicated that the item was not applicable to his family.

Category 5 - Strategies

In this study, "Strategies" was defined as skills and techniques needed to assist parents in each of the following areas: (a) effective parenting, (b) stress management, (c) instruction, (d) communicating with support persons, and (d) advocating for their children with disabilities. A total of six questions were

designed by the researcher. Out of six questions, one question addressed strategies for reducing and coping with stress and anxiety, one addressed strategies for effective communication with family members, educational professionals, and medical professionals, two addressed behavior management strategies, one addressed advocating for children with disabilities, and one addressed strategies for teaching social and self-care skills. The range of possible scores was 6 to 30.

Overall, parents indicated a moderate level of need as indicated by their scores (see Table 8). Parents' scores ranged from a mean of 2.88 (on strategies for managing behaviors of children with disabilities) to a mean of 4.00 (on strategies for reducing and coping with stress and anxiety). For most items, the mode was 3.00 (i.e., a moderate level of need) with two items having modes of 4.00 (i.e., a high level of need for strategies for reducing and coping with stress and anxiety, and strategies for teaching social and self-care skills to children with disabilities).

Insert Table 8 about here

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1. Reduce and cope with stress and anxiety (17/17). Less than half of the parents (35%) indicated a very high level of need for strategies on how to reduce and cope with stress and anxiety. One of these parents commented that she was recently divorced, had a quick temper, and did not make enough money to support her family, pay for daycare, and her apartment. In addition, she mentioned that since she had no support from her ex-husband, she could not go back to school. An additional six parents (35%) indicated a high level of need, followed by a moderate level of need indicated by four parents (24%), and a low level of need indicated by one parent (6%). The parent who indicated a low level

Table 8

Preschool Sibling Survey Descriptive Statistics: Category 5 - Strategies

Item Description	Mean	Mode	Standard Deviation
1. Reduce and cope with stress and anxiety	4.00	4.00	0.94
2. Communicate with family, school staff, and medical professionals	3.29	3.00	0.99
3. Manage behavior of child without disabilities	2.88	3.00	1.41
4. Manage behavior of child with disabilities	3.65	3.00	1.27
5. Advocate for child with disabilities	3.53	3.00	1.84
6. Teach child with disabilities	3.71	4.00	1.21

of need commented that she had adequate support from her spouse and family, particularly during difficult times.

2. Communicate with family, school, and medical professionals (17/17). Over half of the parents (53%) expressed a moderate level of need for strategies on how to effectively communicate with family, school staff, and medical professionals. Three parents (18%) indicated a very high level of need, three parents (18%) indicated a low level of need, and two parents (12%) indicated a high level of need. Parents who expressed a high level and very high level of need for these types of strategies, also indicated that they had at least 12 years of education. In fact, three of these parents had 3 or 4 years of University education.

3. Manage behavior of child without disabilities (17/17). Less than half of the parents (35%) expressed a moderate level of need for strategies on how to manage the behaviors of their children with disabilities. Four parents (24%) indicated no need, followed by a very high level of need as indicated by three parents (18%), a high level of need as indicated by two parents (12%), and a low level of need for these strategies as indicated by two parents (12%).

4. Manage behavior of child with disabilities (17/17). Six parents (35%) expressed a very high level of need for strategies on how to manage the behaviors of their children with disabilities. Three of these parents also indicated a very high level of need for strategies on managing the behaviors of their children without disabilities. Five parents (29%) expressed a moderate need for these strategies, followed by a high level of need as indicated by three parents (18%), a low level of need as indicated by two parents (12%), and no need as indicated by one parent(6%). Additionally, parents who expressed very high or high levels of need for these strategies, also indicated a very high level of need

for information on how to handle their childrens' behaviors (i.e., item 2 of Category 1 - Information).

5. Advocate for child with disabilities (16/17). Less than half of the parents (35%) indicated a moderate level of need for strategies on how to advocate for their children with disabilities. Five parents (29%) expressed a very high level of need for these strategies, followed by no need as indicated by three parents (18%), a low level of need as indicated by one parent (6%), and a high level of need as indicated by one parent (6%). One parent (6%) did not provide a rating or comment for this item.

6. Teach child with disabilities (17/17). Six parents (35%) indicated a high level of need for strategies on how to teach their children with disabilities (e.g., self-care skills). An additional five parents (29%) indicated a very high level of need for these strategies. One of these parents commented that she needed assistance with toilet training and teaching her child to be more independent with eating and dressing skills. Parents who indicated a very high level of need for these strategies also indicated a very high level of need for strategies on how to manage the behavior of their children with disabilities (item 3 of Category 5 - Strategies). Three parents (18%) indicated a moderate level of need, followed by a low level of need as indicated by two parents (12%), and no need as indicated by one parent (6%) for these types of strategies.

Telephone Interview Results: Items 1 to 8

Parents interested in participating in a follow-up telephone interview with the researcher, were asked to complete the consent form at the end of the Preschool Sibling Survey. Parents provided a phone number, and a convenient time for the researcher to call. The parents were also informed that they would be contacted once the surveys were collected and summarized. A total of seventeen parents

(100%) indicated that they were interested in the follow-up telephone interview. Fifteen out of the 17 parents (88%) participated; two parents (12%) could not be reached because their phones were not in service at the time of the follow-up call.

As stated earlier, a total of 8 statements and 8 open-ended questions comprised the telephone interview. After the researcher read each statement, the parents were asked to indicate whether they agreed or disagreed with the statement. Subsequently, the parents were asked to provide any comments, suggestions and/or recommendations regarding each statement. Eight open-ended questions were designed to ascertain parents' comments, suggestions, and/or recommendations regarding ways in which parents of children with disabilities might assist other parents in enhancing the quality of life for their preschool-aged children without disabilities, their children with disabilities, and their family. The telephone interviews lasted an average of 30 minutes. The reported range was 30 minutes to 45 minutes.

Four out of eight closed-ended questions and open-ended questions were designed to access additional information on parents' perceptions of the needs and concerns of the family when one of their children has a disability (i.e., items 1 to 8). In this section, the researcher indicates the percentage of parents who agreed and disagreed with the statements. Comments, concerns, and/or recommendations were summarized, and follow each statement accordingly. All of the parents (N=15) answered all of the questions listed on the telephone interview form (see Appendix E).

Access to local support groups for families of children with disabilities - Question #1. Fourteen parents (93%) agreed with the following statement: "It is becoming more difficult for parents to access local support groups that provide

family support, information regarding respite care, and financial assistance." One parent (7%) commented that she has never been involved in any local support groups, and therefore, was unable to agree or disagree with this statement. Another parent who agreed with this statement commented that he has had to fight for any type of financial assistance and parent relief services he has received. "With all the cut backs, parents having children with and without disabilities have to beg for any kind of assistance from Handicapped Children's' Services. My mother has helped me by sewing clothes for my son and babysitting when she can." One parent commented that she was unable to access this type of information from her doctors or Handicapped Childrens' Services. "We didn't know who else to go to."

Suggestions and/or recommendations regarding access to local support groups - Question #2. One parent commented that parents of children with disabilities can contact their local health unit for this type of information. "When I needed assistance, I would ask my local health nurse or my doctor. Some parents go through Catholic Social Services or Alberta Family and Social Services Office."

One parent, who agreed with Question #1 commented that she found the local health unit to be of little assistance. "The hand-outs had very little information and the staff didn't explain things very well. The best information came from the In-Home Consultant." Another parent commented that "there are support groups like the Autism Society and Parent's Executive, but not all parents can attend these groups. I don't attend any myself because I find I am beyond that point. I went to a few support groups when my son was first diagnosed."

One parent indicated that her early education program was excellent for assisting parents in finding local support groups. "There was a Parents Advisory

Committee that provided information sessions. Also, handouts specific to different parenting issues were also available from the Early Education Coordinator and the In-Home Consultant. I also received a great deal of assistance from Community Behavior Services. My child was out of control, and they really helped me to get her behaviors under control."

Parent-professional communication - Question #3. Fifteen parents (100%) agreed with the following statement: "There is a need for increased parent-professional communication regarding the needs and concerns of preschool-aged siblings of children with disabilities."

Types of professionals - Question #4. When asked what type of professional parents would feel comfortable with when discussing issues concerning their preschoolers without disabilities, five parents (33%) indicated a psychologist or psychiatrist, and eight parents (53%) indicated a professional at the school level (e.g., In-Home Consultant). One parent (7%) identified parents who have had similar experiences, and commented that "we need to speak with people who listen and don't use all the medical and educational terminology. Sometimes, we need to talk to others who have had the same kinds of experiences." One parent (7%) did not identify any type of professional; however, she commented that this individual had to be a good listener. "Too many professionals don't listen. They just give their opinions and don't listen to what the parents have to say. I want to talk and discuss issues like each child is an individual. Too many put children with disabilities into a group. I would be afraid that this would happen to my children without disabilities as well. Doctors and nurses should avoid developmental levels. What I mean is they should avoid saying your child should be able to do this at this age or say that your child will never be able to do this. This is wrong. They need to start listening to the parents. We know our children."

Assist and encourage cooperative play between siblings Question #5. Fifteen parents(100%) agreed with the following statement: "Parents need to encourage and help their preschool-aged siblings of children with disabilities to play cooperatively with their brothers and sisters with disabilities."

Suggestions or recommendations regarding cooperative play - Question - #6. It is interesting to note each parent commented that sometimes the parent will need to initiate and facilitate play between the children. One parent commented that his son has difficulties playing independently with his younger sister without disabilities. "I find that I need to initiate play with different types of toys and my children follow me. I try to treat them the same as much as possible, and I give both children a great deal of praise and hugs. It's so much work, but my son does not have friends in the neighborhood who he can play with. The school is teaching him how to play with other children, and I try to continue with these play skills at home." Another parent indicated that her children do not play cooperatively very often; however, this may be typical for their age levels. "I find myself having to separate them because it's too frustrating for me to teach them how to play together all the time. I'm just too tired."

Expectations for appropriate behavior - Question # 7. Thirteen parents (87%) agreed with the following statement: "Parents need to remind their preschoolers without disabilities that expectations for appropriate behavior are different from those of their siblings with disabilities." Two parents (13%) disagreed with this statement, and both parents commented that expectations for appropriate behavior were the same for both children.

Suggestions or recommendations regarding expectations for appropriate behavior - Question #8. One parent said, "I suggest that parents try to treat each child the same. If you don't, the child without disabilities will look for attention in

other ways. Also, the child may reject her sister with a disability if she sees that she is being punished for something that was also done earlier by her sister with a disability. We really try to include her as much as possible in what we are doing. We try to be consistent and make punishment appropriate to the behavior by teaching our children."

One parent who agreed with the statement made in question 7 commented that she needed to talk openly with her preschooler without disabilities. "We tried to explain to her why her brother did some things. We would set it up by encouraging her to act in certain ways that would allow for her to teach her brother. For example, we encouraged our son with disabilities for using his speech. We would do the same for his sister without disabilities. In fact, she learned new words that her brother brought home from school, and during his speech sessions. This made her feel better, and it didn't look like we were favoring her brother over her. It also made our son feel good because he was also a teacher for his sister."

Research Question 2

What are parents' perceptions of the needs and concerns of their children with disabilities, and their preschoolers without disabilities as identified during the survey, and during the follow-up telephone interview?

Survey Results: Part 2 - Categories 6 and 7

Part 3 of the Preschool Sibling Survey addressed potential needs and concerns of children with disabilities, and their preschool-aged siblings without disabilities in two different categories. The results from each category are presented in the following section. First, the researcher defines the category and describes the types of items designed by the researcher for that category Then, the information collected from Part 3 of the Preschool Sibling Survey are

summarized in terms of group responses to each of the questions. The researcher statistically described each survey item using measures of central tendency (i.e., mean and mode), and measures of variability (i.e., standard deviation). Tables 9 and 10 present each of the items with the corresponding mean, mode, and standard deviation for each item. Following this section, the researcher presents each item with a statement specific to the number of respondents who responded to each item in parentheses. Group responses and comments provided by respondents to each item follow.

Category 6 - Characteristics of Your Child(ren) with Disabilities

The term "characteristics" was defined as descriptions of particular traits specific to the children with disabilities, as expressed by their parents. For purposes of this study, the researcher designed a set of seven commonly expressed needs of preschoolers with disabilities, as perceived by their parents. Out of the seven questions, one question addressed independence with self-help skills, one addressed self-esteem, three addressed playing with other children, one addressed appropriate behavior, and one addressed participation in community activities. The range of possible scores was 7 to 35.

Parents' scores ranged from a mean of 2.53 (encourage child to participate in community activities) to a mean of 4.53 (encourage independence with self-help skills). Three items had a mode of 2.00 (i.e., seldom needed), and three items had a mode of 5.00 (i.e., always needed to encourage independence with self-help skills, help child to recognize and feel good about him/herself, and help child to understand expectations for appropriate behavior and consequences for unacceptable behavior). See Table 9 for a summary of the results.

Insert Table 9 about here

Table 9

Preschool Sibling Survey Descriptive Statistics: Category 6 - Characteristics of Children with Disabilities

Item Description	Mean	Mode	Standard Deviation
1. Encourage independence with self - help skills	4.53	5.00	1.23
2. Help child to recognize and feel good about him/ herself	4.30	5.00	0.99
3. Expectations for appropriate behavior	4.59	5.00	1.12
4. Play with siblings without disabilities	3.65	2.00	2.00
5. Play cooperatively with each other	3.47	3.00	1.70
6. Encourage play with other children	3..41	2.00	1.81
7. Encourage participation in community activities	2.53	2.00	1.23

1. Encourage independence with self-help skills (16/17). Over half of the families (53%) expressed that they always had to encourage their children with disabilities to be as independent as possible with personal-care and self-help skills. One parent commented that when a child has autism, encouraging independence is ongoing. Another parent commented that although her child is totally dependent, they encouraged her to do as much as she could for herself. Four families (24%) indicated that they needed to somewhat encourage independence with these skills, followed by three parents (18%) who indicated that they usually had to encourage independence with these skills. One parent (6%) did not respond to this item.

2. Help child to recognize and feel good about him or herself (17/17). Over half of the parents (59%) indicated that they always had to help their children with disabilities to recognize and feel good about the positive things that they do. Three of these parents commented that they praise all of their children when they do a great job, and one of the parents commented that verbal praise and hugs should be given to all children. Three parents (18%) expressed that they usually had to help their children, followed by three parents (18%) who somewhat needed to help their children, and one parent (6%) who seldom needed to help their children.

3. Expectations for appropriate behavior (16/17). Almost half of the parents (47%) indicated that they always had to help their children understand there are expectations for appropriate behavior and consequences for unacceptable behaviors. One of these parents commented that they tried to help their child understand that certain behaviors are inappropriate. Another parent commented that she needed a way to assist her child with a profound visual impairment to see and understand that her sibling without disabilities is receiving fair discipline

and encouragement. Six parents (35%) indicated that they usually needed to help their child, followed by two parents (12%) who indicated that they somewhat had to help their children. One parent who indicated that he usually had to help his child, commented that it is difficult when your child is autistic and doesn't understand inappropriate behavior. One parent (5.9%) did not respond to this item.

4. Encourage play with siblings (15/17). Four parents (24%) indicated that they seldom needed to encourage their children with disabilities to play with their preschool-aged siblings without disabilities. One of these parents commented that her son had a profound visual impairment; however, had no difficulties playing with his younger sister without disabilities. She added that they fight sometimes. Another three parents (18%) indicated that they usually needed to encourage their children, followed by three parents (18%) who somewhat needed to encourage their children, three parents (18%) always needed to encourage their children, and two parents (12%) never needed to encourage their children to play with their siblings without disabilities. One parent commented that she tries very hard to get her son to play with his siblings without disabilities; however, it isn't always easy. Another parent commented that he tries to encourage his son to play with his sister without disabilities, even if this is sitting beside her on the couch and looking at a book with her. Two parents who did not provide a rating, commented that their preschoolers without disabilities were too young to play with their brothers and sisters with disabilities; however, one of these mothers indicated that she involved her child with disabilities in what her other daughter was doing as much as possible. Two parents (12%) did not respond to this item.

5. Play cooperatively with each other (16/17). Less than half of the parents (35%) indicated that they somewhat had to help their children to play

cooperatively with each other. One of these parents commented that she will need to help her children more as they get older. Three parents (18%) indicated that they always had to help their children, and an additional three parents (18%) indicated that they usually had to help their children. Two parents (12%) indicated that they seldom need to help their children play cooperatively. One of two parents (12%) who indicated that they never had to help their children, commented that if his child with disabilities takes the toys away, his sister usually gets a different toy. The parent added that his daughter prefers to play without her brother. One remaining parent (6%) did not respond to this item.

6. Encourage play with other children (16/17). Four parents (24%) indicated that they always had to encourage their children with disabilities to play cooperatively with other children. All four parents indicated that their children with disabilities had behavior disorders in addition to other disabilities. Additionally, the parents indicated a very high need for information and personal support regarding behavior management and play skills (items 2 and 3 in Category 1 - Information). Four parents (24%) indicated that they somewhat needed to encourage their children, followed by three parents (24%) who seldom needed to encourage their children, and two parents (12%) who usually needed to encourage their children. One of two parents (12%) who never needed to encourage her children, indicated that her child had a speech/language impairment and was moderately dependent with routine tasks. The other parent indicated that her child had a developmental delay and was independent with routine tasks. One parent (6%) did not respond to this item.

7. Encourage participation in community activities (17/17). Five parents (29%) indicated that they seldom needed to encourage their children with disabilities to participate in community-based activities. One of the parents

commented that they registered their daughter for community-based sports programs, and added that their daughter loved them. Four parents (24%) indicated that they never needed to encourage their children with disabilities because they were unable to access appropriate programs for their children. One parent commented that there were few choices for parents, particularly when the child has a mild hearing impairment, speech/language impairment, and learning disabilities. Another four parents (24%) indicated that they somewhat needed to encourage participation, followed by three parents (18%) who usually needed to encourage participation. The remaining parent (6%) indicated that he always needed to encourage participation. This parent identified his child with disabilities as autistic, non-verbal, and as having severe learning disabilities. This parent also indicated that he always need to encourage his child with disabilities to play with other children (item 6 in Category 6 - Characteristics of Your Child(ren) with Disabilities).

Category 7 - Characteristics of Your Child(ren) without Disabilities

The term "characteristics" was defined as descriptions of particular traits specific to the preschool-aged siblings without disabilities, as expressed by their parents. For purposes of this study, the researcher designed a set of 11 commonly expressed needs of preschool-aged siblings of children with disabilities, as perceived by their parents.

Out of the 11 questions, three questions addressed encouraging and teaching the siblings with disabilities to be independent (e.g., self-help skills), two questions addressed self-esteem, two questions addressed playing with other children, one question addressed playing with the siblings with disabilities, one addressed participation in community activities, and two questions addressed personal support about concerns and fears regarding their siblings' disabilities. The range of possible scores was 7 to 35.

Parents' scores ranged from a mean of 2.82 (encourage child to participate in community activities) to a mean of 4.30 (help child to recognize and feel good about him/herself). Four items had a mode of 1.00 (i.e., never), and two items had a mode of 5.00 (i.e., always needed to help their child to recognize and feel good about him/herself, and praise child for taking care of the sibling with disabilities). See Table 10 for a summary of the results.

Insert Table 10 about here

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1. Help child to recognize and feel good about him or herself (17/17). Over half of the parents (59%) indicated that they always needed to help their preschool-aged children without disabilities to recognize and feel good about the positive things that he or she did. Each of these families had preschool-aged siblings who were younger than their brothers or sisters with disabilities. In one family, there were two older children with disabilities and one preschooler without disabilities. Four parents (24%) indicated that they usually had to help their children, and each family consisted of younger brothers and sisters without disabilities. One of these families consisted of four children, the oldest child had a speech/language impairment, and his siblings without disabilities ranged from 1 year up to 3 years of age. Two parents (12%) indicated that they seldom needed to help their children, followed by one parent (6%) who somewhat needed to help her child.

2. Remind child to allow sibling to do things for him or herself (16/17). Four parents (24%) indicated that they always had to remind their preschoolers to let their brothers and sisters with disabilities to do as many things as possible without assistance. Each parent indicated that their preschoolers without

Table 10

Preschool Sibling Survey Descriptive Statistics: Category 7 - Characteristics of Children without Disabilities

Item Description	Mean	Mode	Standard Deviation
1. Help child to recognize and feel good about him/ herself	4.30	5.00	1.05
2. Remind child to allow sibling to do things for him/ herself	3.77	2.00	1.56
3. Play with children in the neighborhood	2.88	1.00	1.90
4. Encourage play with sibling(s)	3.12	2.00	2.00
5. Encourage child to participate in community activities	2.82	3.00	2.13
6. Encourage child to assume some care	3.24	3.00	2.11
7. Encourage open communication	3.59	1.00	2.50
8. Reassure child is not responsible for the disability	3.53	1.00	2.50
9. Reassure child will not contract the disability	3.06	1.00	3.00

Item Description	Mean	Mode	Standard Deviation
10. Praise child for taking care of the sibling	4.24	5.00	3.00

disabilities were younger than their brothers and sisters with disabilities. The family sizes ranged from four-to-five. In total, two preschool-aged siblings of c children with disabilities were male and two were female. Four parents (24%) indicated that they usually needed to remind their children. Three of these four parents indicated that their preschoolers were younger than their brothers and sisters with disabilities; however, one family had a child who was a twin of the child with disabilities. One parent indicated that her preschool-aged daughter without disabilities was older than her sister with disabilities. The family sizes range from four-to-six. In total, there were six female siblings and two male siblings without disabilities. Four parents indicated that they somewhat needed to remind their children (24%). Another four parents (24%) who seldom needed to remind their children, indicated that their preschoolers were younger than their brothers and sisters with disabilities. All four parents indicated a family size of four. In total, there were three female siblings and one male sibling without disabilities. The remaining parent (6%) commented that this item was not appropriate to their family.

3. Play with children in the neighborhood (16/17). Less than half of the parents (29%) indicated that they never needed to encourage their preschoolers to play with other children of their own ages in the neighborhood. One of these parents commented that his daughter enjoyed playing with other children in the neighborhood. Four families (24%) somewhat needed to encourage their preschoolers, followed by three parents (18%) who seldom needed to encourage their preschoolers, two parents (12%) usually needed to encourage their preschoolers, and two parents (12%) indicated that they always needed to encourage their children to play with others. One of these two parents commented that her oldest son had difficulties playing with other children in the

neighborhood. She added that her son plays with younger children because the older ones tend to beat him up or pick on him. The remaining parent (6%) did not respond to this time.

4. Encourage play with brothers and sisters with disabilities (16/17). Five parents (29%) indicated that they seldom needed to encourage their children to play with their brothers and sisters with disabilities. One parent indicated that her four year old son with Down Syndrome, and his 3 year old sister always played well together. Four parents (24%) indicted that they never needed to encourage play, and four parents (24%) always needed to encourage play. One of these four parents commented that his preschooler without disabilities tries to investigate play with her brother; however, she soon becomes bored and moves onto another toy because her brother doesn't play like other children. An additional two parents (12%) somewhat needed to encourage play, and one parent (6%) usually needed to encourage play. One remaining parent (6%) did not respond to this item.

5. Encourage child to participate in community activities (15/17). Almost half of the parents (41%) indicated that they somewhat needed to encourage their preschoolers without disabilities to participate in community-based activities with children of their own ages. Five parents (29%) indicated that they never needed to encourage participation, followed by three parents (18%) who seldom needed to encourage participation. One of the three parents commented that she had few or no choices of appropriate recreational programs for her preschooler without disabilities. The remaining two parents (12%) did not respond to this item.

6. Encourage child to assume some care (15/17). Five parents (29%) indicated that they somewhat needed to encourage their preschoolers without

disabilities to be responsible for some care of their brothers and sisters with disabilities. Four parents (24%) seldom needed to encourage their preschoolers, followed by three parents (18%) who never needed to encourage, and two parents (12%) who usually needed to encourage their preschoolers. One parent (6%) indicated that she always needed to encourage her 2 year old daughter to assist her 4 year old brother with a profound visual impairment. Two parents (12%) indicated that the item was not applicable yet for their preschoolers without disabilities. These parents had 2 year old children without disabilities, and older brothers and sisters with disabilities.

7. Encourage open communication (14/17). Four parents (24%) indicated that they somewhat needed to encourage their children to talk about their concerns or fears about their siblings' disabilities. Four parents (24%) expressed that they never needed to encourage their children, followed by three parents (18%) who always needed to encourage their children. An additional three parents (18%) seldom encouraged their children. Two parents commented that their preschoolers were too young to understand the situation. Another parent commented that her preschooler was only 3 years old and had not really shown any fears of her sister's disabilities yet. Three parents (18%) did not provide a rating and indicated that the item was not applicable to their preschoolers at this time.

8. Reassure child is not responsible for the disability (14/17). Almost half of the parents (47%) indicated that they never needed to reassure their children that they were not responsible for their siblings' disabilities. One of these parents commented that her 4 year old daughter without disabilities had not assumed responsibility for her sister with disabilities. The parent added that, to her knowledge, she never gave their daughter any reason to feel that she should be

responsible. She also commented that these feelings may arise as their daughter gets older. Another parent stated that both parents told their 2 year old son without disabilities that his 4 year old brother was born like he is and it is nobody's fault. Four parents (24%) expressed that they always needed to reassure their preschoolers without disabilities. It is interesting to note that these four families consisted of 4 year old and 5 year old siblings of children with disabilities. One parent (6%) indicated that she seldom needed to reassure, followed by one parent (6%) who somewhat needed to reassure her preschooler without disabilities. The remaining three parents (18%) indicated that this item was not applicable to their preschoolers at this time.

9. Reassure child will not contract the disability (13/17). Over half of the parents (53%) indicated that they never needed to reassure their children that they would not contract their brothers' or sisters' disabilities. Three parents (18%) expressed that they seldom need to reassure their children, followed by one parent (6%) who expressed that she always needed to reassure her child. This parent did not provide any comments regarding this issue. Four parents (24%) indicated that this item was not applicable to their preschoolers at the time. These parents indicated that their preschoolers without disabilities ranged from 2 years up to 4 years of age.

10. Praise child for taking care of the sibling (14/17). Six parents (35%) expressed that they always needed to praise their children for the time they spent taking care of their siblings with disabilities. These parents indicated that their preschoolers without disabilities ranged from 2 years to 5 years of age. Three parents (18%) indicated that they seldom needed to praise their children, followed by two parents (12%) who indicated that they never needed to praise their children, and two parents (12%) who indicated that they somewhat

needed to praise their children. One parent commented that if he is busy upstairs, he will ask his daughter to run down and check on her brother. When she comes upstairs again and tells her father what her brother is doing, her father praises her. Another parent commented that she never thought about praising her daughter for assisting in this way. Three parents (18%) indicated that this item was not applicable for their preschoolers yet. One parent (6%) did not respond to this item.

11. Encourage child to teach sibling with a disability (14/17). Five parents (29%) indicated that they seldom needed to encourage their children without disabilities to teach their brothers and sisters how to do different tasks (e.g., dressing, eating, playing). One of the parents commented that their 4 year old daughter without disabilities is very mothering and enjoys teaching her sister. Another parent stated that his 3 year old daughter was a little too young to assume this type of responsibility. Four parents (24%) indicated that they always needed to encourage their children, followed by three parents (18%) who indicated that they somewhat needed to encourage their children, and two parents (12%) who indicated they never needed to encourage their children. The remaining three parents (18%) indicated that this item was not appropriate for their preschoolers yet.

12a. Expectations for appropriate behavior (17/17). Twelve parents (71%) indicated that expectations for appropriate behavior were the same for each child in the family. Five parents (29%) indicated that expectations were not the same. One parent commented that her child, who is totally dependent, needs to be tolerated when it comes to inappropriate behaviors. She stated that she and her husband needed to discipline their children differently. Another parent commented that her daughter with disabilities displays some inappropriate self-

stimulating behavior, and due to her lack of speech, some of her strategies for expressing her dislikes or need for attention are not appropriate. She also indicated that this was not appropriate for their older daughter without disabilities. One father commented that his son with disabilities was not toilet trained, and his daughter without disabilities would dirty her pants from time to time. The parent stated that he needed to tell his daughter that it was okay for her brother because he could not help it. The father told his daughter that it would help him is she used the toilet, and help her brother learn how and when to use the toilet.

Additional comments. Parents were asked to provide any additional comments that they felt might be helpful for this study. Comments, concerns, and/or recommendations were summarized below:

-It is hard on my daughter when her brother dirties his pants. She says that her brother is bad again. I try to explain he is not bad but different. My daughter just turned three and I think in another year she will understand more. Since my daughter does not have a mother around, this may make things harder for her.

-Our children with disabilities need a little more attention then the other two children; however, we love them all the same.

-My oldest child used to be very outspoken and self-assured. I have noticed since our child with the disability has been requiring more time for appointments, physiotherapy, etc., I've noticed her personality has changed. She is very sensitive to the needs of others - which is good but she is also now very easily "hurt". If she is reprimanded, i.e., told in a firm voice not to play with an electrical cord, she cries and says her feelings are hurt. If I tell her she can't have a chocolate bar at 8:00 a.m., she cries and says I've hurt her feelings, that it's not fair, and that I don't like her. My husband and I have continually re-assured her and praised her.

-My children get along fairly well. She copies him frequently but she has taught him many of things. With my son in school, he has learned many things and

brought it home and showed his younger sister (e.g., how to talk). However, he wants absolutely nothing to do with potty training. His sister sees this and refuses to even sit on it. They play off each other a great deal.

-Our daughter is the twin sister of our handicapped son and seems to be developing an increasing awareness of his disability and concern for his health, and an increased determination to help him.

-We have four adopted children ages three, four, five and seven. Three are disabled and therefore are never responsible for another sibling; although, they naturally help each other.

-I am a single parent on social assistance with a child who is hyperactive and has Attention Deficit Disorder. Life for me is very difficult. It is difficult to get help when I need it as the help never seems to be within reach. I have to try and depend on the church, Handicapped Childrens Services, and Community Behavior Services. Coordinating all this plus medical appointments is extremely stressful and makes life for me much less enjoyable.

Telephone Interview Results - Items 9 to 16

Four out of eight closed-ended questions and open-ended questions were designed to access additional information on parents' perceptions of the needs and concerns of their children with disabilities and their preschool-aged children without disabilities (i.e., items 9 to 16). In this section, the researcher identifies each statement and indicates the number of parents who responded to each item in parentheses. Subsequently, the researcher indicates the percentage of parents who agreed and disagreed with the statements. Comments, concerns, and/or recommendations were summarized and follow each statement accordingly.

Care-giving responsibilities - Question # 9. Fifteen parents (93%) agreed with the following statement: "Preschool-aged siblings of children with disabilities had

more care-giving responsibilities that their same-age peers without brothers and sisters with disabilities." One parent (7%) disagreed with this statement, and commented that she never places her daughter in a situation where she is solely responsible for taking care of her sister with disabilities.

Suggestions or recommendations regarding caregiving responsibilities - Question #10. Out of fifteen respondents, only two parents indicated that they had some suggestions for parents in this situation. One mother commented that siblings, no matter how old they are, need to know that they are not responsible for their brothers and sisters with disabilities. "It's important that they be encouraged to help them; however, they should not feel like they are completely responsible for them. In our family, my younger daughter without disabilities wants to assist her sister with disabilities by pointing out her faults (e.g., ___ can't put her coat on). I think she does this so that she can get attention from me." The mother also commented that she encourages and praises her younger daughter when she helps and encourages her sister with disabilities. "I want her to feel like she is doing something good, so that she can get my attention in a positive way."

The second mother who disagreed with the first statement, commented that it is very important to encourage your child with disabilities to do as much for themselves as possible, and try not to have their siblings do everything for them. "In our situation, we need to include our preschool-aged daughter in the caregiving tasks so that she doesn't feel left out. For example, when I needed to change a diaper, I would say, 'Okay, time to change ___'s diaper. Would you like to help mommy? You can bring the diaper and help me.' You see, you need to include your children without disabilities. If you don't, they will try to get your attention in other ways."

Parent time and attention given to children with disabilities - Question #11. Fourteen parents (93.3%) indicated that they agreed with the following statement: "Generally speaking, children with disabilities require more time and attention from parents than their brothers and sisters without disabilities." One parent (7%) disagreed with this statement, and commented that she and her husband made an effort to treat each child the same. "It depends on the age and the severity of the disability; however, we need to remember that we have to provide equal time and attention for each child as best as possible."

Suggestions or recommendations regarding quality time with children - Question #12 . All of the respondents commented that it was important to spend time individually with each child. One mother commented that "it is difficult to spend time individually with each child; however, I ask grandma or dad to take our son with disabilities on a special activity, and I do a special activity with my daughter without disabilities (e.g., make cookies at home) . We plan one special activity for each week. Also, this gives our son some quality time with his dad." One father commented that he had lunch with his son with disabilities on Thursday, and did a special activity (e.g., shopping) with his daughter on another afternoon. Additionally, the father commented that it was important for him to organize joint activities for he and his children at the same time (e.g., swimming).

One parent who disagreed with Question #11 commented that she and her husband provided one to one activities for each child, and also facilitated opportunities for joint activities as a family. "It's important to remember that our child with a disability is no different than any other preschoolers without disabilities. We try to focus on the similarities instead of the differences. Our child with a disability may need extra help with some things, but we try not to make a big deal out of it. Our preschooler without disabilities has individual

needs as well. This is why we try to spend as much quality time with each child individually, and as a family."

Communication with family about disabilities - Question #13. Fifteen parents (100%) agreed with the following statement: "Generally speaking, parents who openly communicate with the family about their child's disability(ies), are more likely to influence positive adjustment by the siblings without disabilities."

Suggestions or recommendations regarding communication with siblings of children with disabilities - Question #14. Seven of the 15 parents provided suggestions regarding communication with siblings of children with disabilities. One parent indicated that she needed to be very honest and open regarding her son's special needs and inappropriate behaviors. "We found this very important as our daughter without disabilities began to imitate her brother's inappropriate behaviors. She was two then. Now, she is older and seems to be more aware of her brother's differences and limitations. However, she has learned a great deal from her brother also. As he went for speech therapy, he would bring new words home, and his sister began saying them." Another parent commented that she tried not to make a big deal over family meetings. "I sat down with my younger daughter, and explained to her that there were differences between her and her brother." The parent also commented that she encouraged her daughter to assist in teaching her brother and feel proud of her ability to assist him in this way. Another parent commented that he was unable to communicate openly with his younger daughter because she was too young. "She would see her brother dirty his pants, and then start to have toileting accidents herself. It was then that I had to sit down with her explain the differences between her brothers special needs and her own. I encouraged her to help me by asking her to help her brother to be clean, and go to the toilet."

Other parents commented that it was important to provide information that the siblings could handle, but "don't force it." Also, two parents commented that it was important to let their children without disabilities know that they could talk with them and ask questions about their siblings with disabilities whenever necessary. One parent said the information needed to be age-appropriate and presented in such a way that the family would be sensitive to the needs of the child with disabilities. "The siblings may be frustrated with their brothers and sisters with disabilities if they have limited speech. It's very easy for the siblings to become frustrated with their brothers and sisters with disabilities. I emphasize the similarities when my daughter asks 'why?' questions. For example, my daughter without disabilities is 4 years old and asks, 'Why can't ____ put her shirt on by herself?', 'Why does ____ get to sit in the front seat?', 'Why does ____get to eat with that fork?' The important thing is to provide your children with straight answers without acting too much on the question. Emphasize how your child can be mommy's helper and praise him/her for being a good teacher."

Severity of disability and sibling adjustment - Question #15. Fifteen parents (93%) agreed with the following statement: "The severity of the disability influences a sibling's adjustment to the arrival of a brother or sister with a disability." One parent (7%) commented that she could not agree or disagree with this statement because "it depended on the age of the sibling without disabilities. If the sibling is close in age to his newborn brother or sister with a disability, she may not notice any differences or experience any adverse effects. If the child is about 3 or 4 years old, you would need to assist this child with the arrival of his/her newborn brother or sister, regardless if the child had a disability or not. There would be some period of adjustment for any child."

Easing sibling's adjustment to arrival of brother or sister with a disability - Question #16. Surprisingly, only one parent had comments and/or recommendations regarding strategies for assisting parents who want to ease adjustment to the arrival of a brother or sister with a disability. This parent, commented that "naturally the children without disabilities are going to question why this baby is here. It doesn't matter if the baby is disabled or not. To ease the adjustment; however, I would suggest being very careful with the amount of attention given to the newborn. Try to include the children together in daily activities as much as possible. It's hard work to include each child, particularly when you are in a hurry. I learned to make my children a priority, and I put housework, appointments, etc., second. If people didn't like my house, I learned not take this personally because my children were more important."

Comments regarding Preschool Sibling Survey and Telephone Interview.

It is interesting to note every parent commented that the survey and telephone interview were good ways to ascertain the needs and concerns of their family and preschool-aged siblings of children with disabilities. One parent commented that parents feel more comfortable to speak on the telephone because it's less threatening. Also, this parent commented that it gave her an opportunity to voice all of her concerns without interruptions from other parents or professionals. Another parent suggested that this study would have really helped her after her child with disabilities was born. "I didn't know what to do when my child was born. I wanted to see another parent with a child like mine before I took my child home. I learned that care giving was basically the same for her as it was for my other daughter. I also needed assistance with my child without disabilities, as she was very close in age to their sister with disabilities. I think this type of interview and survey would give parents an opportunity to give their

concerns and perhaps access some assistance from the professionals, and other parents in these situations." One father commented that he thought this was a great format for accessing parents' concerns, and added that he would be interested in any follow-up studies of this nature.

Summary of the Chapter

This chapter reviewed the findings pertaining to the two research questions serving as the foundation for this study. Chapter 5, Discussion, summarizes and examines the results with regard to implications for preschool-aged siblings of children with disabilities, brothers and sisters with disabilities, parents, and professionals working with families of children with disabilities. Limitations of the study and implications for future research are also considered.

CHAPTER 5

Discussion

This chapter summarizes and discusses the results of the study. First, parents' perceptions of current family needs, as indicated in Part 2 - Categories 1 to 5 of the Preschool Sibling Survey, and in items 9 to 16 of the follow-up telephone interview, are summarized. The most commonly reported areas of low or no need, and areas of very high need are presented with a discussion of the potential impact on family relationships; more specifically, sibling relationships. Recommendations for service providers, educational professionals, and parents are presented after a discussion of items identified as areas of very high need. Subsequently, a summary of parents' perceptions of current needs of their children with disabilities, and their preschool-aged children without disabilities, as identified in Part 3 - Categories 6 and 7 of the Preschool Sibling Survey, and in items 1 to 8 of the follow-up telephone interview is presented. Items identified as areas of low or no need are listed, followed by items identified as very high areas of need. Recommendations for professionals and parents follow. Limitations of the study, and implications for using the researcher's and parents' comments, suggestions, and/or recommendations to assist professionals and parents in enhancing the quality of life for their children with disabilities, and the lives of their preschool-aged siblings without disabilities are included. Finally, this section suggests possible directions for future research.

Summary of the Study

Background and Rationale. The purpose of the study was to investigate parents' perceptions of the unique needs of their preschool-aged children having

brothers and sisters with disabilities. The researcher was particularly interested in examining the development and socialization of sibling relationships within the family. Potential influences from both within and outside the family were identified as parents indicated their current levels of need in each of the following areas: (a) information, (b) professional support, (c) community/generic support, (d) family support, and (e) strategies. Additional information pertaining to family needs, the current needs of their children with disabilities, and their preschool-aged children without disabilities were identified as indicated by the parents in the survey, and during the follow-up telephone interview. The information presented in this study includes demographic information (Part 1), the current levels of need for the families as indicated by the parents (Part 2 - Categories 1 to 5), the needs of their children with disabilities (Part 3 - Category 6), and the needs of their preschool-aged children without disabilities (Part 3 - Category 7). This material was subsequently summarized and described in terms of group responses. Comments and recommendations provided in the survey followed the descriptive summary of the closed-form questions.

The follow-up telephone interview was designed by the researcher to discuss parents' general concerns of their family (items 1 to 9), and the needs of their preschool-aged children without disabilities (items 9 to 16), in more detail. Responses to closed and open-form questions were summarized and described in terms of group responses. Comments and recommendations provided by the parents followed the summary of results to the closed-form questions.

The literature contained past and current studies investigating sibling relationships within the context of the family. The impact of potential influences from both within and outside the family to explain relationship differences among sibling pairs in which one child has a disability were reviewed and included:

(a) characteristics of the individual siblings, (b) the effects of individual sibling characteristics on parenting, (c) the effects of individual parent characteristics on parenting, (d) the effects of family characteristics on parenting and on the sibling relationship, and (e) parenting and the sibling relationship (Stoneman and Brody, 1993). The literature review mainly focused on the direct influence of individual child characteristics on sibling relationships. These disability-related variables included age, gender, temperament, care demands, serious health risks, cognitive/language competence, social/adaptive competence, physical or sensory disability, aggression, and noncompliance. Direct and indirect influences exerted by the parents, child-rearing strategies, and family emotional climate, on the sibling relationships were also reviewed.

Results of the Study

First, Research Question 1 is presented, followed by the lowest and highest areas of family needs in the Preschool Sibling Survey (i.e., Part 2 - Categories 1 to 5), as indicated by the parents (see Appendix F). Comments, concerns, and/or recommendations elicited during the telephone interview are also included in the appropriate categories. The implications of these results and possible measures that could reduce high areas of need will then be considered.

Research Question 1

What are parents' perceptions of the needs and concerns of families having children with disabilities and preschool-aged children without disabilities as identified during the survey, and during the follow-up telephone interview?

Category 1 - Information. The descriptive statistics in Table 4 indicated that most parents identified a moderate level of need for "information" specific to child development, child-rearing strategies, community and support services, access

to financial services, siblings of children with disabilities, educational programming, and medical information services. The most commonly reported areas of low need or no need were information on how to play and talk with the children (item 3), information on the growth and development of children (item 4), information on how to access financial services (item 5), information on how to access respite care services (item 8), information on how to access babysitting services (item 9), information on their child's medical condition, equipment, and supplies(item 13), and information on parent support groups (item 14). Parents commented that they currently had this information available to them and/or they knew how to access this information; however, none of these parents indicated who provided the information. It is important to note that less than a quarter of the parents indicated high or very high levels of need for the same items. Some parents commented that they did not know how to access this information, and/or they found it difficult to access information specific to their childrens' disabilities, and for their preschool-aged children without disabilities. One parent in particular expressed a very high level of need for a support group for single parents.

As indicated in the literature review, the added stress of not having access to this type of resource might place additional demands on the parents. Interactions between family members (e.g., husband-wife interactions, sibling interactions) may be at risk if parents do not have effective coping strategies and formal/informal support persons to assist them (Barber et al., 1988). Preschool-aged siblings of children with disabilities may also require basic information regarding their brother's or sister's disabilities (Powell & Ogle, 1985; Simeonsson & Bailey, 1986; Turnbull & Turnbull, 1990).

The most commonly reported areas of high need were information for accessing future school placements (item 11), and information for accessing

specialized therapy services (item 13). Although these two items focus on separate issues, they are related in their potential impact on the family members. For instance, a program change may be one direct source of stress and vulnerability for the parents, and indirectly affect the sibling relationship Similarly, access to specialized therapy services, and funding for these services, may be of great concern to many parents (Kopriva et al., 1991). This may be particularly true for parents who do not know how to access this information. Furthermore, it was reported in some articles that the potential for even more demands and sources of stress might occur when parents find that they are unable to take care of their own physical and mental needs. Single parents and families of low socioeconomic status may also be at risk (e.g., Barber et al., 1988; Stoneman & Brody, 1993).

Although parents may access this type of information via the Early Education Program (e.g., Transition Handbook), their local Health Unit, and/or the Early Intervention Programs, this information alone may be inadequate without active parent involvement. Other prevention strategies, such as strategies aimed at supporting and encouraging parents to take an active part in the transition process are currently effected by the Early Education Programs, with much success. Increased parent involvement in their childrens' early intervention program has also shifted from solely teaching parents how to manage their childrens' behaviors, and teach their children functional skills, to encouraging family involvement and providing family support by focusing on the unique needs of the families. For example, the literature indicated that families requiring information on access to specialized therapy services for their children with disabilities, may differ in terms of their financial demands, time available to access this type of service, access to transportation, or other restrictions

(Stoneman and Brody, 1993). In addition, families requiring information on how to access future program placements, may differ in their ability to locate and decide upon appropriate school placements, having confidence in their ability to act as informed decision-makers, expressing views about their child's needs which may differ from the service providers, and in their ability to access formal and/or informal support systems to assist them in making appropriate school placement choices.

Recommendations.

The service delivery of information is ever-changing. Unfortunately, current research suggests that the most natural information resource for families (e.g., neighbors, family members) may not be aware of programs and/or special services for families having children with disabilities. In addition, formal support systems (e.g., medical and educational professionals) may not always be up to date on the latest resources, services, and/or programs for these families (Winton, 1993).

A "central clearinghouse" for information on existing provincial resources, programs, family support groups, and services would provide these families with the information they need to act as informed decision makers (e.g., A Guide to Services for Albertans with Disabilities, 1993). As printed materials become outdated, constant updating of useful information is critical. In addition, parents who know how to access different service options, and would be willing to share this information with other families, would add to the value of this manual. In particular, parents might know of local community programs that have been effective at normalizing activities for their children with disabilities, and local sibling support groups and programs for siblings of children with disabilities. Also, some parents may know how to access general information on siblings of

children with disabilities (e.g., Sibling Information Newsletter). Appendix G contains recommended readings for families of young children with and without disabilities. References specific to parent training, parental support, childrens' books, and videotapes for use with the brothers and sisters without disabilities, and journals for parents and siblings of children with disabilities are listed according to types of disabilities.

According to the literature, educational professionals who provide treatment, educational, and/or support programs can be most helpful to parents by assisting them in developing and strengthening informal support systems (e.g., extended family members, friends, and neighbors). Also, improved coordination between formal support systems (i.e., educational and medical professionals) may best assist families with children requiring a range of services (Bubolz & Whiren, 1984; Dunst , Trivette, & Cross, 1986; Zimmerman, 1984).

Category 2 - Professional Support The descriptive statistics in Table 5 represent the need for "Professional Support" in the following areas: (a) respite care and baby-sitting services (item 1) , (b) availability of parent support groups and professional services (items 3 and 4), (c) education programs (items 5 and 6), (d) counseling and information school workshops for parents (items 7 and 8), and (e) discussion/information sessions with medical and educational professionals, and parents in similar situations (items 9-11). The most commonly reported areas of low need were provision of babysitting care services (item 2), parent support groups (item 3), daycare program for child without disabilities (item 6), and counseling for the family (item 7). One parent who indicated no need or low need for parent support groups, also commented that she belonged to one parent support group. The remaining parents provided no comments, and did not indicate any parent support groups that they currently

attended. It is possible that these parents were currently accessing professional support services, and therefore indicated low or no need for this type of service. Other parents may not have required this type of support at the present time.

It should be noted that some parents (6% - 24%) indicated high or very high levels of need for the items listed above. One parent in particular, expressed very high levels of need for each item. She indicated that given her financial situation, it was important for her to access a support group for single parents having children with disabilities. The literature supports this finding as studies have indicated that families with poor financial situations may spend a great deal of time maintaining the household, and managing day to day routines (D'Alonzo & Lazar, 1991). Consequently, there may be little extra time for the parent to share with the children or spend by him/herself.

The most commonly reported area of high need was a daycare program or preschool program for their children with disabilities (item 5). Each parent indicated that their children with disabilities currently attended an Early Education Program for part of the day in a self-contained classroom. No additional information regarding school and/or community programs that their children may have attended for the other part of the day was provided. It is possible that some of these parents find themselves feeling confused over the types of available programs, and the specific program best suited to the needs of their children. Parents might not know where to start in locating a preschool program for their children, what qualities they should be looking for when they visit preschools, how to determine what they want from a preschool program, what to do if they are unhappy with what they find in the community, and how to prepare their children for a transition to an afternoon preschool program. These parents may need to confront issues surrounding their child's disabilities, as transitions may

serve to reaffirm their child's differences. Siblings attending the same preschool may face challenges during a transition to an integrated setting. For example, the brother or sister without a disability may feel responsible for his/her sibling with a disability (e.g., Winton, 1993).

Another item worth discussion is the number of parents (59%) who expressed high and very high levels of need for professional services for their children with disabilities. More specifically, parents underlined the need for speech therapy for their children entering a Kindergarten placement in September, 1992. It is possible that parents may not be able to afford private speech therapy services for their children. In addition, the waiting list for accessing speech services through the Board of Education may be extensive. Both of these variables may create additional stress on the resources of the parents.

With respect to accessing local support groups for these families, 14 out of 17 parents (93%) indicated during the telephone interview that it was becoming more difficult to access local support groups that provided family support, information regarding respite care, and financial assistance. One parent commented that it was difficult to access financial assistance, and parent relief services without a struggle. He further commented that an extended family member needed to assist him by sewing clothes for his children, and providing relief when she was able.

Recommendations

For families having children with disabilities, there is an undeniable need for outside help and support. As indicated in the results, this need may be temporary or permanent; however, many parents have come to accept and deal with this type of assistance. Although less than one third of the parents indicated a high or very high level of need for babysitting services, it is possible that these

parents need the services of reliable and competent babysitters. These individuals must be capable of assuming all relevant responsibilities. As indicated in the literature, routine household duties may become overwhelming when added with the additional responsibilities of raising preschool-aged children, where one of these children has disabilities. The literature supported the notion that ongoing demands and concerns experienced by these parents may effect the parents' attitudes towards parenting, parental expectations for each child in the family, styles of parent-child interactions, and interactions between siblings (Brody et al., 1986; Long et al., 1987; Stoneman & Brody, 1993).

The availability of professional supports and services is an invaluable resource for families having children with disabilities. Providing parents with information and more opportunities to talk with the In-Home Consultants and Coordinators regarding preschool programs for their children with disabilities may reduce some anxiety. A strong informal support network which assumes some of the caretaking responsibilities for a child with disabilities and the preschool-aged siblings without disabilities can greatly assist these parents. Friends who are also parents of children with disabilities can be an invaluable source of companionship and support as well as a source of information on daily management. Community support networks can be a valuable resource for the management of stress. For example, the Early Education Programs could host a self-help information evening where parents learn from each others experiences about how to anticipate and manage stressful situations (i.e., diagnosis of a child's disability). Nevertheless, the total family unit must be considered in establishing external systems of support. Information and professional support services should be easy to access, and local advocacy groups need to be

established so that parents can receive the kinds of information and services they need to care for their children with and without disabilities. Parents who participated in the telephone interview stated that the Early Education Programs were excellent for assisting parents in finding local support groups. Other parents recommended their local health unit, Catholic Social Services, or Alberta Family Social Services Office.

Category 3 - Community/Generic Support The descriptive statistics in Table 5 indicated that about half of the parents indicated low or no need for personal support from other families having children with and without disabilities, medical professionals, human service professionals, clergy, as well as access to community recreational programs, and transportation services. The most commonly reported areas of low need were availability of transportation services for the child with disabilities (item 1), availability of transportation services for child without disabilities (item 2), assistance in locating a doctor (item 6), and meet with Minister, Priest, or Rabbi (item 8). A few parents (6% - 12%) expressed high or very high levels of need for the former items. One parent in particular commented that availability of transportation services for providing their children access to community activities was a very high need because both parents were currently employed during the day and some evenings.

The most commonly reported area of high and very high need was the availability of recreational programs for their children with disabilities (items 4). Some of these parents also indicated a high or very high level of need for recreational programs for their children without disabilities. It is possible that these parents were unable to locate after-school recreational programs that were suitable to their child's needs. For other families, local recreational programs for preschoolers with and without disabilities may be non-existent. Consequently,

opportunities to develop positive social relationships within their peer group, in a community setting, may be reduced significantly. The literature indicated that children with disabilities were at higher risk for fewer opportunities for social interaction with their same-age peers, resulting in unsuccessful attempts at establishing community-based friendships (Guralnick & Groom, 1988; Stoneman et al., 1991).

Recommendations

The acquisition of interaction skills in a socially active environment are critical for many young children with disabilities. Children attending an Early Education Program have many opportunities for developing social interactions in an environment where they observe, acquire, and practice with their peers and educational staff. Chances of these skills generalizing across settings are great when these children have opportunities to practice them outside of school in integrated settings. However, as the results indicated, these children may not have as many opportunities to select and interact with typically developing children as social partners in integrated settings.

As educators, other professionals, and parents, the implications are obvious. We must both encourage and support the development and generalization of social interaction skills in community-based settings. Typically developing children with age-appropriate social skills, good verbal communication skills, attend to tasks for longer periods of time, and follow adult directions may function as excellent peers in a community based recreational program. If community based recreation programs are not offered, or are inappropriate to the needs of preschool-aged children with disabilities, professionals may need to improve social interactions by intervening within naturally occurring contexts and situations during the child's program, while providing more opportunities for

students to generalize these skills in a community setting (e.g., community swimming program, local grocery store, community library). As indicated in the literature, children who acquire more advanced adaptive skills may participate in more cooperative activities with their siblings, friends, and other children in community-based settings (Stoneman et al., 1987; 1989).

Parents may be able to find more information on local community recreation programs from their local Community and Recreation Centre. In Alberta, additional contacts include: (a) Rick Hansen Centre, (b) Alberta Special Olympics Association, (c) Alberta Sports and Recreation Association for the Blind, (d) Alberta Deaf Sports Association, (e) Little Bits Riding Club, and (f) Canadian Wheelchair Sports Association-Alberta Section. Also, lists of local recreation programs and costs could be provided to the families from the Early Education Programs.

Finally, It would be very valuable to include a training component for Community and Recreation leaders and summer staff working with children with disabilities (e.g., Lakeside Camp for Children with Disabilities in Gimle, Manitoba). Information and practical strategies specific to facilitating social interactions between preschoolers with disabilities, and their same-age peers in community based recreation programs may be included as a training component for Community and Recreation leaders and summer staff working with these children (e.g., Lakeside Camp for Children with Disabilities in Gimle, Manitoba). Educational professionals working with these children, and parents would be excellent resource persons. This type of collaborative effort between the school and community programs may maximize resources and develop successful integrated services that meet the needs of these children and their families.

Category 4 - Family Support. The descriptive statistics in Table 7 indicated a moderate level of need for personal support from spouses, extended family members, and personal friends. In addition, the parents indicated a moderate level of need for more quality time with immediate family members. The most commonly reported areas of low need were more support from spouse during difficult times (item 5), more emotional support from extended family members (item 6), and more emotional support from friends (item 7). It is important to note that five parents expressed high and very high levels of need for items 6 and 7. Two of these 5 parents identified themselves as single parents. It is possible that in some family situations, the single parent may be supported by extended family members and others providing social support; whereas in other situations the parent may be truly isolated and trying to cope with few friends or family members available to help (e.g., Barber et al., 1988; Schilling, Gilchrist, & Schinke, 1984; Sherman & Cocozza, 1984).

The most commonly reported areas of high need were more quality time with children with disabilities (item 2), and more time for myself (item 8). Parents who indicated a high or very high level of need for item 2, gave the same rating for more quality time with their children without disabilities.

Although parents provided no additional comments with their ratings, it is possible that these families currently receive some form of assistance from their spouse, friends, relatives, and parents having children with disabilities. Although the literature indicated that families with children having disabilities might be more likely to experience marital conflict (Brody et al., 1986; Callan & Noller, 1986), it is possible that major sources of strength for these families are personal characteristics of the parents (e.g., personal wellness), and the quality of their marital relationship. Research has indeed demonstrated that the marital

relationship is of central importance as a source of support during times of stress (Sherman & Cocozza, 1983).

Recommendations

The literature identified a number of factors which may influence a parents' ability to cope with additional demands placed on the family when one of the children has a disability including socioeconomic status, ages of the parents, family size, occupation, past experiences, personality characteristics, number and age of siblings, and personal wellness (Barber et al., 1988; D'Alonzo & Lazar, 1991; Stoneman & Brody, 1993). Of all these factors, it is possible that personal wellness is ignored by many parents who continue to meet the daily needs of their children. Yet, if the parent(s) are not taking care of themselves, how can they provide adequate care for their children? Identifying the need for more quality time with their spouses as well as time for themselves is a good starting point.

It is no surprise that extended family and friends can be a major source of support for families having children with disabilities. This type of support may assist these parents with perceiving acceptance, and receiving encouragement and assistance with their children (Gallagher et al., 1983).

Professionals also have the ability to become outstanding sources of personal support for parents; however, our professional behavior must vary considerably depending on the needs of the family. Even in families having children without disabilities, resources such as respite and more time to spend with the spouse can be very important. The degree of stress for many families may be associated with the availability of adequate child-care services for their children, and the amount of assistance they receive from friends and extended family members. Consequently, adequate support would appear to be an important

mediator of stress in many families with and without disabilities.

During the telephone interview, 14 out of 15 parents (93%) agreed that there was a need for increased parent-professional communication regarding the needs and concerns of their children without disabilities. Some parents added that they needed increased communication to discuss issues regarding the entire family. When asked what type of professional parents would feel comfortable with, parents selected educational professionals, medical professionals, and parents who can relate with similar experiences. One parent in particular indicated that she needed to speak with professionals who would be good listeners.

We, as educational professionals, have the important job of assisting our families in accessing the support services they need to help themselves personally, and their families. As each family has unique needs, it is critical that we continue to work on understanding the interests, priorities, and resources of each family, and take an individualized approach to family support (Bailey & Winton, 1989; Turnbull & Winton, 1983). For some families, we may need to focus on parent training activities specific to areas of adaptive difficulty, or on developing more extensive systems for respite care. We may need to encourage some of our parents to attend parent groups, where they can share experiences and feelings with other parents who have similar experiences. For other families, friends and family who have shown particular interest in the children with disabilities might be provided with information and short-term training in areas that would be useful to the family (Barber et al., 1988; Winton, 1993).

Category 5 - Strategies. The descriptive statistics in Table 8 indicated that most parents identified a moderate level of need for "strategies" needed to assist them in the following areas: (a) effective parenting, (b) stress management,

(c) instruction, (d) communicating with support persons, and (d) advocating for their children with disabilities.

Twelve out of 16 parents indicated high and very high levels of need for strategies on reducing and coping with stress and anxiety (item 1). As mentioned in the literature review, families of children with disabilities may encounter a number of unique problems as they attempt to adjust to the needs of their children with disabilities (e.g., Bernheimer, Young, & Winton, 1983; Fortier & Wanlass, 1984; Schilling et al., 1984; Stoneman & Brody, 1993). Parents may experience increased financial demands resulting from the needs for special equipment, special medical care, and special programs. Some parents may experience marital conflict, depression, anger, guilt, and anxiety as a result of these extra demands (Cameron et al., 1993).

Twelve out of 17 parents indicated high and very high levels of need for strategies on effective communication skills with family, school staff, and medical professionals (item 2). As indicated in the results, all of these parents had at least 12 years of education. Three parents had 3 or 4 years of University education. It is possible that parents may find it difficult to communicate with other professionals and families in similar situations because they feel uncomfortable talking about particular issues, and/or parents might feel they may not be able to state their opinions if they are different and conflict with those given by professionals and other parents.

Seven out of 17 parents indicated high and very high levels of need for strategies to help them manage the behavior of their children without disabilities (item 3). Although no parents commented on any specific behaviors of concern and/or types of assistance they needed, it is possible that children with disabilities are at some risk for developing social interaction difficulties and

behavior problems. They may have difficulties as a result of the disability. Other children may have had inadequate opportunities to socialize with same-age peers. Nevertheless, children with disabilities are ready to be active, contributing members of our society if we can teach them the skills and arrange supports that meet their needs.

Nine out of 17 parents indicated high and very high levels of need for strategies to help them manage the behavior of their children with disabilities (item 4). As indicated in the literature review, some of the challenging behaviors displayed by these children may be typical of their age group (Powell & Ogle, 1985). However, it is possible that preschool-aged siblings of children with disabilities may be at risk for displaying attention-seeking behaviors, particularly when the parents need to give more time to meet the needs of their children with disabilities. At the same time, preschool-aged siblings of children with disabilities may experience feelings of guilt, resentment, neglect, and shame. The extent to which siblings experience stress and display challenging behaviors may depend upon the age, sex and birth order of the sibling, the type and severity of the disability, and the quality of interactions between the child without disabilities and his/her parents (Powell & Ogle, 1985; Stoneman & Brody, 1993).

Six out of 17 parents indicated high and very high levels of need on strategies to help them advocate for their children with disabilities (item 5), and five more parents indicated a moderate level of need. Genuine parental involvement requires participation in decision-making concerning their children with disabilities. If we, as professionals, want parents to be active partners, then we need to allow parents to look at all of their options and decide what is the best plan of action for their children.

Twelve out of 17 parents expressed a high and very high levels of need for strategies on how to teach their children with disabilities (e.g., self-care skills) (item 6). A few parents commented that they needed strategies specific to toilet training, feeding and dressing skills. As indicated in the literature review, and comments provided by the parents, a child's special needs can have a significant impact on the parents. Routine caregiving tasks, such as feeding, toileting, and dressing, may be made more difficult with the severity of a child's disabilities (e.g., Barber et al., 1988; Gallagher et al., 1983; Vadasy, Fewell, Meyer, & Schell, 1984). Consequently, the child becomes more dependent on the parents for help and assistance in routine tasks of living and communication. Much of a parent's time may be spent assisting with these tasks; however, parents continue to ask for new strategies to assist their children in becoming as independent as possible with these skills.

Recommendations

As indicated in earlier sections, parents of children with disabilities may need to cope with multiple stresses in raising their child. Both formal and informal support networks are important to these families, perhaps more than professional support. Some possible coping mechanisms which may assist parents to combat stress include: (a) relaxation strategies, (b) self-praise and self-instruction, and (c) problem solving which involves selecting possible solutions from a variety of options then acting on the chosen alternative. These types of coping mechanisms are positive responses that may enhance a parent's confidence, self-esteem, and ultimately enhance long-term functioning of parents.

The ability to enhance interpersonal skills may assist parents in establishing contacts and building social supports. For professionals, it may be necessary to

offer workshops for parents on how to request help and, in turn, offer support to other parents. Parents could discuss different dimensions of effective communication. Unmet needs and issues regarding their childrens' program for example, and strategies for planning in advance before parents meet with education staff might be additional topics of discussion. This type of service may provide parents with a better understanding of personal coping and social supports. If they encounter difficulties in caring for their children with disabilities, parents can use their new skills to access personal and social resources.

Professionals may play a big part in the lives of children with disabilities and their families. One of the important ways that we, as professionals, can assist parents is by providing emotional support. In addition, information (i.e.,handouts, newsletters, and videos) and parent information sessions on strategies for managing typical and atypical problem behaviors in preschool-aged children with and without disabilities can be very useful for parents. Parents may be confused about what they should expect from their children with disabilities, and what type of control they should exert over their behavior (i.e., limit setting). The literature indicated that parents in these situations may have difficulties with setting expectations for appropriate behavior, and utilizing strategies that foster equal treatment of the siblings (Block et al., 1981; Emery et al., 1984). Consequently, professionals may need to assist these families in exploring this issue and other disciplinary issues that all parents face rather than focusing on problem behaviors as pertaining solely to parents of children with disabilities.

During the telephone interview, 13 out of 15 parents (87%) agreed that parents needed to remind their preschoolers without disabilities that expectations for appropriate behavior are different from those of their siblings with disabilities. These parents recommended that parents talk openly with their preschoolers

without disabilities about the inappropriate behaviors. One parent commented that she needed to explain to her daughter why her brother with disabilities did certain things. She added that parents can set up situations where the siblings are encouraged to teach their brothers and sisters with disabilities. She also commented that the siblings feel better and it doesn't look like the children with disabilities are being favored.

For professionals, proactive planning should involve providing parents with information regarding some types of behaviors they should be aware of during critical periods so that parents can plan for unexpected difficulties. For example, common behavior problems such as attention-seeking behaviors and aggression related to time and attention given to the child with disabilities should be discussed with the parents before these types of behaviors escalate. Open and honest communication with information that is age-appropriate may be the key to successful adjustment of preschool-aged siblings of children with disabilities (Stoneman & Brody, 1993). Strategies to assist parents in organizing quality time with each child, and strategies for including the preschool-aged siblings in daily tasks, may be useful to many parents.

With respect to advocating for children with disabilities, many parents know their children better than anyone else. They generally know what their children can do on a daily basis, what they like, and what kinds of things will motivate them to learn new skills. It is important that parents are encouraged to communicate this type of information to professionals working with the family, and their children with disabilities. Parents need to be encouraged to develop ideas about what their childrens' needs are and be provided with the steps to getting those needs met. By becoming active participants in the program-planning process, parents can ensure that results are appropriate to their

childrens' needs. If critical needs are not being met, parents need to address them when they speak with the teacher alone, and/or other service providers on the transdisciplinary team. Most of these issues may be resolved at this level, and may not require more intensive action. If parents are unsuccessful, they may need to access other persons who frequently help parents resolve educational problems.

Research Question 2

What are parents' perceptions of the needs and concerns of their children with disabilities, and their preschool-aged siblings without disabilities as identified during the survey, and during the follow-up telephone interview?

A summary of lowest and highest areas of needs and concerns of the children with disabilities, and their preschool-aged siblings without disabilities as indicated by the parents in Part 3 - Categories 6 and 7 of the Preschool Sibling Survey are presented (see Appendix F). Comments, concerns, and/or recommendations elicited during the follow-up telephone interview were included in the appropriate categories. The implications of these results and possible measures that could reduce high areas of need will then be considered.

Category 6 - Characteristics of Your Child(ren) with Disabilities. One quarter of the parents indicated that they seldom needed to encourage their children with disabilities to play with their siblings without disabilities (item 4), encourage their children with disabilities to play with other children (item 6), and encourage their children with disabilities to participate in community-based activities (item 7). Some of these parents commented that their children with disabilities had no difficulties initiating interactions with their siblings without disabilities and with their peers. Parents who indicated that they seldom needed to encourage their child with disabilities to participate in community-based activities commented that

they were unable to access appropriate programs for their children.

For other parents, encouraging the children with disabilities to play with their siblings and peers was more challenging. One parent commented that she tried hard to facilitate interactions between her two children; however, it was not easy. During the telephone interview, all parents agreed that parents needed to encourage their preschool-aged children without disabilities to play cooperatively with their brothers and sisters with disabilities. A review of literature indicated that parents of young children with and without disabilities may need to facilitate cooperative interactions between the siblings (Stoneman & Brody, 1993). The authors suggested that parents initiate interactions and facilitate opportunities for the children to practice prosocial skills (e.g., cooperation, smiling, turn-taking).

Eleven out of 17 parents indicated that they usually and always needed to encourage their children with disabilities to be as independent as possible with personal-care and self-help skills (item 1). Thirteen out of 17 parents indicated that they always needed to help their children with disabilities to recognize and feel good about the positive things that he/she does (item 2). Thirteen out of 17 parents indicated that they needed to help their children understand that there are expectations for appropriate behavior and consequences for unacceptable behaviors (item 3).

Recommendations

As indicated in the literature review, young siblings in general, spend a great part of the day playing and interacting together (Pepler et al., 1984). Differences in the quantity and quality of social interactions between sibling pairs may vary when one of the siblings has a disability. A disability can affect a child's social skill development in various ways. For example, children with limited motor movements may be unable to wave or smile. Children with visual impairments

may not look toward others, and may not smile. Delayed communication skills may also serve to limit social interactions. Consequently, many of these children require instruction in basic skills for social interaction (Guralnick & Groom, 1988; Stoneman et al., 1991; Winton, 1993).

Educational staff and parents may use direct instruction to teach specific social skills (e.g., smiling and turn-taking). For example, an instructor might teach a student to wave good-bye to her bus driver in three steps. First, the instructor might say, "Jane, wave good bye." Then, the instructor provides a model (i.e., waves good-bye), and provides hand over hand assistance (i.e., wave Jane's hand for her) if needed. Education staff also facilitate social interactions among the children using social toys (i.e., puppets, toys with auditory and visual reinforcement). Peer models are also effective for assisting instructors with specific social skills. Play environments are typically set up so that peers are likely to be responsive to social initiations made by peers with disabilities.

Parents indicated that they attempted to encourage and facilitate social play between their children at home, and in community settings. One parent recommended during the telephone interview that parents get involved by playing with their children. He suggested that parents select toys if they need to, and model the play skills for the children. In addition, while playing with the children, the parent needs to make the play experience positive by providing praise and hugs for their efforts. Another parent recommended that parents facilitate and encourage play; however, try not to overdo it. Also, she mentioned that parents try to treat each child the same so that one child doesn't feel that he/she is being favored.

It was very interesting to listen to one single parent who commented during the telephone interview that she found it very difficult to facilitate play because

she was too tired by the end of the day. She commented that it was easier to separate the children and let them play by themselves. Given the extra demands placed on this parent, it is no wonder that the parent had little energy to spend playing with the children. In these situations, it is critical that these parents be able to seek help in meeting the child's and family's needs by accessing family members, friends, and/or neighbors. Some families may need help with household duties so that parents have more time to spend with their children.

Encouraging independence with self-help skills, and helping a child with disabilities to feel good about themselves, may take a great deal of effort on part of the parents and the school. The literature indicated that this may be particularly true when mental, physical, or challenging behaviors slow, or limit the development of these skills (Snell, 1993). Nevertheless, self-care skills are critical for maintaining good health and reducing dependence on parents, school staff, and/or siblings. Appropriate dressing and grooming skills are critical for acceptance in a peer group, and may improve access to integrated community environments.

It is no surprise that parents need to encourage their children to recognize and feel good about themselves (Forte, 1991; Pincus, 1988, 1990). Poor self-esteem may be attributed to a feeling of helplessness and repeated failures. Therefore, access to community-based recreation programs may contribute to the improvement of personal wellness if it assists the child in meeting new children, and new experiences that are positive for the child.

As indicated in an earlier section, parents may need to remind their children about expectations for appropriate behavior. This may be typical for all parents with preschool-aged children; however, knowing when to set limits with children having disabilities may be a challenge for some parents. Parents continue to

need personal support from informal support systems and formal support systems in this area. Some parents commented during the telephone interview that they made an effort to treat each child alike; expectations for appropriate behavior were the same for each child. One parent commented that treating each child the same would prevent the preschool-aged child without disabilities from displaying attention-seeking behaviors. The literature review supported the recommendations of these parents. Although expectations for appropriate behavior may be different for the children, parents are advised to handle inappropriate behaviors in a calm, firm, and predictable manner. This may reduce the chances of adverse feelings as a result of differential parent attention and/or reactions to inappropriate behavior (Allen, 1984; Crary, 1990; Wyckoff & Unell, 1984; Stoneman & Brody, 1993).

Category 7 - Characteristics of Preschool-Aged Children without Disabilities. The descriptive statistics in Table 10 indicated that almost half of the parents never and seldom needed to encourage their children without disabilities in each of the following areas: to play with other children of their own age in the neighborhood (item 3), to play with their siblings with disabilities (item 4), to participate in community-based recreation activities (item 5), to assume some care for their siblings with disabilities (item 6), and to talk about their concerns or fears about their sibling's disability (item 7). Almost half of the parents (47%) indicated that they never needed to reassure their children that they are not responsible for their sibling's disability. Over half of the parents (53%) indicated that they never needed to reassure their child(ren) that they would not contract their sibling's disability (item 9). Two of these parents commented that their preschool-aged children without disabilities were too young to understand what was going on. It is possible that these parents may have tried to talk with their

children regarding their sibling's disability; however, the literature suggested that parents can provide clear and understandable information to their children at a level that is appropriate for them to handle (Lobato, 1985; Powell & Ogle, 1985).

It is important to note that two or more parents indicated that they usually or always needed to encourage their children to talk about their concerns and fears, reassure them that they were not responsible for their sibling's disability, and reassure them that they would not contract their sibling's disability. Fourteen out of 17 parents indicated that they usually or always needed to encourage their preschool-aged children without disabilities to recognize and feel good about the positive things that they did (item 1). In addition, six parents indicated that they always needed to praise their children for the time they spend taking care of their siblings with disabilities (item 10). In each family, the preschool-aged child without a disability was younger than his/her sibling with a disability.

Recommendations

Preschool-aged siblings of children with disabilities indeed have special needs and concerns of their own as perceived by their parents. Although few parents indicated that they needed to reassure their children that they were not responsible for their siblings' disabilities, and that they would not contract their sibling's disability, it is possible that these preschoolers are especially vulnerable to misunderstanding the disabling condition and experiencing other fears. Preschool-aged siblings can acquire more accurate information about disabilities, treatments, and support for their fears with contracting the disability or disease, by participating in family discussions. In addition, some siblings may feel more comfortable with attending a sibling support group and or information group to increase their knowledge in these areas.

As indicated in the Preschool Sibling Survey and during the telephone

interview, most parents (71%) indicated that expectations for appropriate behavior were the same for each child in the family. Some of these parents commented that equal treatment of the children would prevent the preschool-aged child without disabilities from displaying attention-seeking behaviors. For example, if this parent spent more time responding to the needs of the child with disabilities, her child without disabilities became aggressive towards her child with disabilities to get her attention. Another parent commented that her preschool-aged daughter would question why her brother would get to do things that she wasn't allowed to do. The parent recommended that parents in this situation explain why expectations are different, and use the child without disabilities as a model for his/her sibling with disabilities. Including the children may reduce sibling conflict and facilitate positive interactions between the siblings. In addition, the parents may promote caring attitudes toward their siblings with disabilities. Other strategies recommended during the telephone interview to facilitate more positive interactions between siblings and the parent(s) were to set up guidelines or rules with enforceable consequences, planning special activities for the entire family, individual activities with each parent, and having information periods with the children when concerns or worries would arise.

Although one parent (6%) indicated that she always needed to encourage their preschool-aged children to assume some care for their siblings with disabilities, she did not identify any negative effects on the siblings. More parents (24%) indicated that they always or usually needed to remind their children to let their brothers and sisters with disabilities to do as many things as possible without assistance. Perhaps the role relationship between preschool-aged sibling pairs with one sibling having a disability is naturally more

asymmetrical, with siblings spending some time teaching and caring for their brothers and sisters with disabilities; however, no parents commented on any negative effects at this time. Given that the siblings spend little time provided this type of care for their brothers and sisters with disabilities, the well-being of the siblings may not be negatively affected at this age. It is interesting to note that six parents indicated that they needed to always praise their children for the time they spent taking care of their siblings with disabilities.

During the telephone interview, one parent commented that she avoided placing her daughter in a situation where she was solely responsible for taking care of her sibling with disabilities. Other parents commented that they encouraged their children to assist their brothers and sisters with disabilities; however, they recommended that parents help their children to understand that they are not completely responsible for them. They further added that it was important to praise their children for assisting and encouraging their siblings with disabilities. Unlike the results found in earlier studies regarding the adverse effects of younger siblings assuming caregiving responsibilities to siblings of children with disabilities (Correa et al., 1986; Lobato, 1983; McKeever, 1983), the comments provided by parents indicate that perhaps the role of teacher and caregiver has brought many learning opportunities and an increased understanding of children with disabilities. Parents of older children without disabilities describe their children as being more tolerant and empathic towards persons with disabilities (Lobato, 1983; Powell & Ogle, 1985). As indicated in the literature review, the effects of caregiving responsibilities may be related to gender and age of the siblings of children with disabilities, and the type, frequency, and magnitude of the responsibilities (Stoneman et al., 1987).

Over half of the parents (58.8%) indicated that they needed to help their

children without disabilities to recognize and feel good about themselves. The literature supported the notion that the way in which siblings of children with disabilities perceive their sibling relationship, their satisfaction with the amount of time parents gave them relative to their siblings with disabilities, and types of coping strategies used to adjust to sibling problems may be associated with better adjustment by these children (Stoneman & Brody, 1993). For example, if siblings are unhappy with the amount of time their parents spend with their brothers and sisters with disabilities, they may be at risk for lower self-esteem and anxiety. In addition, siblings may be at-risk if the relationship between them is characterized by negative behavior. During the telephone interview, parents commented that it was important to spend quality time with each child, and as a family. To accomplish this on a weekly basis, one mother indicated that she needed to include the grandmother to take one of the children on a special activity, while the other parent went with the other child.

It is critical that professionals who work with families having children with disabilities spend time investigating the personal wellness and self-esteem of the siblings without disabilities Parents and professionals can work together on assessing the risk factors, the quality of the sibling relationship, and the issues, concerns, and feelings of these children. In order to address the needs of the preschool-aged siblings, intervention may be most effective within the context of the entire family.

Recommendations for Future Research

Future studies on the effects that children with disabilities have on their preschool-aged siblings without disabilities is needed. Although there are limitations with generalizing results from preschool-aged siblings of children with one type of disability from literature on other siblings, more research questions

can be generated. For example, "Does the severity of a child's disability affect the adjustment of a preschool-aged sibling?"; "Does the current education program of the child with a disability have any effect on how the preschool-aged siblings perceive their relationship with their brothers and sisters?"; and "Would an intensive family workshop for parents, preschool-aged siblings of children with disabilities, and their brothers and sisters with disabilities facilitate better adjustment for the preschool-aged siblings of children with disabilities?"

Current literature has opened the door to new research questions, such as the ones listed. Additional information must be collected on all types of influences on the lives of preschool-aged siblings of brothers and sisters with disabilities. More specifically, information on the adjustment period, the quality of social interactions between siblings, and strategies for assisting preschool-aged siblings during the intervention process must be gathered.

It would be interesting to explore similarities and differences in the lives of children with disabilities and their preschool-aged siblings in different cultural places. The cultural place and cultural meanings may affect both the way in which families experienced having children with disabilities and what they did as a result, particularly for issues surrounding caregiving.

Finally, additional research needs to include more studies of individual differences to identify variables affecting sibling relationships. Identifying these variables will be effective in the design of preventive interventions for preschool-aged children of siblings with disabilities and their families.

Limitations of the Study

It should be noted that the current research was limited in a number of ways.

Selections of participants. One limitation arose because it was not possible to have a random sample; as such, all families were not proportionally represented.

Additionally, since the sample size was small (N=17), the researcher could not be confident, within a reasonable limit, that if she should draw a different sample of the same sample size and use the same procedures, that the same results would be approximately obtained. It is possible that parents participating in this study comprised a biased group, therefore limiting the generalization of these results.

Factors affecting the reliability and validity. A critical concern in the study is the fact that the information on preschool-aged siblings of children with disabilities did not come from the siblings themselves, but rather from the parents. To ensure that the answers provided by parents were reliable, the researcher would need to conduct a follow-up study which would compare the siblings' own reports to the past parents' reports. Additionally, the study would need to be replicated with more families.

Another limitation is whether the answers collected would differ with the choice of mother or father as the respondent. Areas of need and concern may also differ according to the gender of the preschool-aged sibling.

The return rate for this study was low. Perhaps parents are becoming more protective of their privacy, and therefore decided not to participate in this type of research study. Other factors including the length of the survey, intrusiveness of the questions, urban/rural residence, gender of the siblings, and socioeconomic status may have made parents reluctant to participating in this study.

Survey Study. Another limitation of the study is that the researcher was unable to investigate variability among preschool-aged siblings of children with disabilities, in terms of social interactions, play and community-based activities, and psycho-social functioning. Given the sample size, the researcher was unable to statistically examine possible relationships between selected demographic data and parents' perceptions of the needs of their family, the

needs of their children with disabilities, and the needs of their preschool-aged children without disabilities.

Summary

In summary, the results provide evidence that indicate the importance of addressing the unique needs of preschool-aged siblings of children with disabilities and their families. Risk factors such as family supports (i.e., psychological strengths and financial resources), professional support, strategies, and information were investigated. Unique needs and concerns specific to preschool-aged siblings of children with disabilities were identified and discussed. In addition, sibling relationships were discussed in terms of reciprocity and complimentarity.

The implications for parents point toward providing honest, direct, and understandable information to their preschoolers without disabilities. This information is needed in order to answer questions about their brothers and sisters with disabilities, their own family, themselves, school, special services, treatment, and other issues. Information would need to be provided in different forms as they progress through various stages of their lives. The findings also point out that the siblings may be strongly influenced by their parents' attitudes and expectations towards their brothers and sisters with disabilities. If the parents are unable to accept their child with a disability, or isolate themselves by not communicating with the family, professionals, and/or parents in similar situations, they may further isolate the siblings without disabilities, and contribute to their lack of information. An empowerment model of service delivery in which parents are assisted to become capable and competent may alleviate some of the many challenges experienced by the parents and siblings without disabilities.

For professionals, the implications are obvious. Parents of children with

disabilities face many challenges related to coping with their child's disability. Issues may begin with the birth of the child and continue throughout the parents' and childrens' lifetime. An integral part of the process of facing these challenges are the professionals who provide a variety of services directed towards treatment, remediation, education, or support for the entire family.

We must continue to support families by showing respect and empathy for the children with and without disabilities, and the parents. Valuing and encouraging parental input in discussions about their children with and without disabilities is critical. There is little doubt that parental knowledge of their children can be invaluable to professionals providing treatment, educational, or support programs.

Improved coordination between these services may also provide benefits for the child with a disability and the family. This is particularly important when the child with a disability requires a range of services. Parents can be the best primary source of information regarding their children with and without disabilities. The parents know how their children feel and understand, and can, in most cases, communicate this to a service provider. It certainly forms a starting point for any intervention or support, and would increase family/professional collaboration and acknowledge the many competencies of families.

Due to the increasing awareness of the needs of preschool-aged siblings of children with disabilities for clear and concise information, it is critical that we, as professionals, also initiate informational programs specific to siblings' ages, particular needs, and interests. We also need to examine the risk factors, the quality of the sibling relationship, and the issues and concerns of these feelings. However, in order to address these needs, we must examine parental influences

and environmental supports and limitations. Additionally, we need to look at factors that contribute to the benefit of having a brother or sister with a disability. This is important for the prevention of problems, as well as for families who are not doing well. We must be sensitive to parents who feel that their preschool-aged siblings of children with disabilities are "too young" to address and understand issues discussed in a sibling group. Other parents might be uncomfortable with family issues that might be shared with everyone in the group. Consequently, we may also need to initiate informational programs within the context of the whole family.

Finally, as professionals, we may also be called upon to demand changes in the current funding system so that families of children with and without disabilities are no longer ill served. Encouraging parents to participate in advocacy groups may be another means of directly serving our parents, and indirectly serving their children with and without disabilities.

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APPENDIX A

Consent Form

Project Title: Parents' Perceptions of the Needs of Preschool Siblings Having Brothers or Sisters with Disabilities.

Investigator:

Darlene M. Tanchak
Graduate Student, Department of Educational Psychology
University of Alberta

Dr. Linda McDonald
Thesis Supervisor
Department of Educational Psychology
University of Alberta

Purpose: The purpose of this study is to investigate the needs and concerns of preschool-aged children of brothers and sisters with disabilities.

Description: Parents with children in one of three Early Education Programs (E. E. P.) are requested to complete the enclosed survey. The survey contains 3 components:
(a) Demographic Information, (b) The Current Needs of the Family, and (c) The Current Needs of Preschool-Aged Children.

If you are interested in participating in this research, please complete and return the survey within two weeks or at your earliest convenience.

At the end of the survey, there is a consent form requesting assistance from parents to participate in a follow-up telephone interview to discuss general needs and concerns of preschool-aged siblings of brothers and sisters with disabilities. If you are interested in participating in a telephone interview, please complete the consent form. However, you do not need to fill out this form if you are only interested in completing the survey.

Confidentiality: Returned surveys will be assigned a number and will be referred to by that number to ensure confidentiality and anonymity. Also, before the data are summarized and analyzed, permission slips to participate in a follow-up interview will be detached so that the researcher does not associate responses from the survey with the comments and concerns elicited during the interview.

All information will be kept confidential. At no time will the name of a child, family or relative appear in the thesis. Returned surveys will be destroyed upon completion of the study.

Benefits: Each program will receive a copy of the study and the results as well as a hand-out with references that will assist the program in meeting the needs of families of preschool-aged siblings without disabilities.

Parents who decide to participate in this study will be providing information that will help other families with preschool-aged siblings of children with disabilities. In addition, the information obtained in this study will be useful for improving: (a) services to families of young children with disabilities and their preschool-aged siblings, and (b) programs for training professionals to work with families.

Consent: I understand that I can withdraw my consent at any time during the conduct of the study.

THIS IS TO CERTIFY THAT I _____
(name of participant)

agree to participate in the above study.

If you have any questions or concerns, please contact Darlene Tanchak at 435-5127, or _____ at _____.
E. E. P. Coordinator phone number

_____ _____
Participant Date

_____ _____
Witness Date

APPENDIX B

Preschool Sibling Survey

The enclosed survey is designed to investigate the needs and concerns of preschool-aged children having brothers or sisters with disabilities, as perceived by their parents.

The survey is made up of three components: (a) Demographic Information, (b) Current Family Needs, and (c) Current Needs of Preschool-Aged Children. The term 'parent' is used to refer to all caregivers of children including birth parents, adoptive parents, and foster parents.

Instructions

1. Please read the instructions and examples provided before completing the survey.

2. If there are questions that do not apply to you or your family, please indicate 'N/A' in the spaces provided.

3. If there are questions that you would not like to answer. please indicate 'N/I' in the spaces provided. All the answers you give will be treated in strictest confidence.

4. Completed surveys may be returned in the self-addressed, stamped envelope provided in your package. An identification number will be used in the upper right hand corner to ensure confidentiality and anonymity.

Identification Number: _____

PART 1

Demographic Data

INSTRUCTIONS: Part 1 of the survey includes questions about you and your family. For each item, please circle the number that best describes your current family situation.

1. Relationship To Children:

   1 Mother **2** Father **3** Other (please specify): _____

2. Age: _____

3. Occupation: _____

4. Educational Background (Circle highest level of education completed)

   1 Less than 12 years **2** 12 years **3** 1 or 2 years at college

   4 1 or 2 years of technical training **5** 3 or 4 years of University

   6 More than 4 years of University **7** Other (Please Specify): _____

5. Marital Status At Present Time (Please Circle)

   1 single **2** married **3** divorced **4** separated **5** common law **6** widowed

Questions 6 to 8 refer to your spouse if applicable

6. Age of Spouse: _____

7. Occupation of Spouse: _____

8. Educational Background of Spouse (Circle highest level of education completed)

   1 Less than 12 years **2** 12 years **3** 1 or 2 years at college

   4 1 or 2 years of technical training **5** 3 or 4 years of University

   6 More than 4 years of University **7** Other (Please Specify): _____

9. Please specify the age and gender for each child in the family who is 5 years of age or younger.

Age (Specify years and months)	**Gender**	
_____	_____male	_____female
_____	_____male	_____female
_____	_____male	_____female
_____	_____male	_____female

Please place a check ( ) next to the name(s) of the child(ren) with a disability

10. Child(ren)'s Disability (Select all that are appropriate)

If you have more than one child with a disability, who is 5 years of age or younger, please use the following codes for answering this question: _____child 1 ____child 2 ____child 3

1 autism **2** behavior disorders **3** cerebral palsy **4** Down Syndrome

5 epilepsy **6** head/spinal cord injury

7 hearing impairment (_____mild_____moderate_____severe_____profound)

8 visual impairment (_____mild_____moderate_____severe_____profound)

9 mental retardation (_____mild_____moderate_____severe_____profound)

10 speech/language impairment

11 learning disabilities

_____other (please specify): _____

Additional Information:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Questions 11 - 13 refer to your child(ren) with disabilities

11. Child(ren)'s age at diagnosis: Child 1: _____ Child 2: _____ Child 3: _____

12. Please circle the number indicating your child(ren)'s current level of independence with routine tasks (i.e., mobility, eating, dressing, personal hygiene). If you have more than one child with a disability, please use the following codes for answering this question: ___child 1 ___child 2 ___child 3

1 Completely Dependent **2** Moderately Dependent **3** Minimally Dependent **4** Independent

Comments:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

13. Please circle the type of program your child is presently attending. If you have more than one child attending an Early Education Program, please use the following codes for answering this question: _____child 1 _____child 2 _____child 3

1 attends an Early Education Program for part of the day in a self-contained classroom.
2 attends an Early Education Program for part of the day in a self-contained classroom and in a Kindergarten classroom.
3 attends an Early Education Program for part of the day and an integrated preschool or daycare program for part of the day.
4 attends an Early Education Program for part of the day and a family day home for part of the day.
5 unsure
6 other (please specify): _____

14. Into which of the following categories would the total annual income for your household fall before 1992 income taxes?

1	under 20,000	**5**	38,000 - 43,000
2	20,000 - 25,000	**6**	44,000 - 50,000
3	26,000 - 31,000	**7**	50,000 or over
4	32,000 - 37,000		

15. If you belong to any support groups (e.g., parent groups), please identify the group and indicate the total hours per week or month that you are involved in each group.

_____
_____
_____
_____

Current Family Needs

Part 2

INSTRUCTIONS: For each statement below, please choose the numerical rating corresponding to the descriptor that best reflects the extent to which that item is a need of yours or your family's at the present time. In choosing a number from 1 to 5, please think of the following descriptors:

no need	*low*	*moderate*	*high*	*very high*
1	*2*	*3*	*4*	*5*

Example:

1. Books (fiction &/or non-fiction) and materials on children with disabilities and their families — 4
2. Information about future planning for your child with a disability — 2

In the above examples, the parent indicated that books and materials were a high need at the present time for the family. Information about future planning for their child(ren) with a disability was rated as having low importance at the present time.

Category 1: Information - To what extent to do you need:

1. books and materials on children with disabilities and their families? _____
2. information on how to handle my childrens' behaviors? _____
3. information on how to play or talk with my children? _____
4. information on the growth and development of children? _____
5. information on how to access financial resources available for families having children with disabilities (e.g., sibling workshops)? _____
6. information about community resources and services available to children having brothers or sisters with disabilities (e.g., sibling workshops?) _____
7. information about community programs and services available for the family (e.g., Parent-and-Tot Program; recreational programs for families)? _____
8. information on how to access respite care services? _____
9. information on how to access babysitting services? _____
10. general information about siblings of brothers and sisters with disabilities (e.g., Sibling Information Network Newsletter, Exceptional Parent Journal)? _____

no need	*low*	*moderate*	*high*	*very high*
1	*2*	*3*	*4*	*5*

11. information about future school placements (e.g., transportation, level of integration)? _____

12. information concerning my child(ren) with a disability's medical condition; medical equipment and medical supplies? _____

13. information on accessing specialized therapy services (e.g., physiotherapy, speech therapy, and/or occupational therapy)? _____

14. information on special groups designed to help parents with specific difficulties or responsibilities (e.g., parent support groups)? _____

15. other (please specify):

_____
_____
_____
_____
_____

Category 2: Professional Support - To what extent do you need:

1. provision of respite care services to my family? _____

2. provision of babysitting services to my family? _____

3. availability of parent support groups and services from provincial and local agencies (e.g., Gateway Association for Community Living, Edmonton Autism Society)? _____

4. availability of professional services for my child(ren) with a disability (e.g., speech therapy, physiotherapy, occupational therapy)? _____

5. a daycare program or preschool program for my child(ren) with a disability? _____

6. a day care program or preschool program for my child(ren) without a disability? _____

7. counseling for my family? _____

8. availability of school workshops and/or information sessions for parents? _____

9. more contact with the In-Home Consultants to discuss concerns with my child(ren) with a disability and his/her sibling(s)? _____

10. more time to talk to my child(ren) with a disability's teacher(s)? _____

11. more time to talk with other parents who have a child(ren) like mine? _____

12. other (please specify): _____
_____
_____
_____

no need	*low*	*moderate*	*high*	*very high*
1	*2*	*3*	*4*	*5*

Category 3: <u>Community/Generic Support</u> - To what extent do you need:

1. availability of transportation services to provide my child(ren) with a disability access o community activities? _____
2. availability of transportation services to provide my child(ren) without a disability access to community activities? _____
3. contact with other parents and siblings having a brother or sister with a disability? _____
4. availability of recreational programs for my child(ren) with a disability? _____
5. availability of recreational programs for my child(ren) without a disability? _____
6. assistance in locating a doctor who understands my needs and the needs of my children with a disability. _____
7. to meet and talk with other parents who have a child(ren) like mine? _____
8. to meet and talk with other parents who have a child(ren) like mine? _____
9. to meet with a Minister, Priest, or Rabbi? _____
10. other <u>(please specify)</u>: _____

Category 4: <u>Family Support</u> - To what extent do you need:

1. more quality time with my child(ren) without a disability? _____
2. more quality time with my child(ren) with a disability? _____
3. more quality time with my spouse? _____
4. more time to discuss problems with my spouse? _____
5. more support from my spouse during difficult times? _____
6. emotional support from extended family members? _____
7. emotional support from friends? _____
8. more time for myself? _____
9. to help my family discuss problems and support each other during difficult times? _____
10. other <u>(please specify):</u> _____

no need	*low*	*moderate*	*high*	*very high*
1	*2*	*3*	*4*	*5*

Category 5: <u>Strategies</u> - To what extent do you need specific strategies to help you:

1. reduce and cope with stress and anxiety? _____
2. effectively communicate with family, school staff, and medical professionals? _____
3. manage the behavior of my child(ren) without a disability? _____
4. manage the behavior of my child(ren) with a disability? _____
5. advocate for my child with a disability? _____
6. teach your child with a disability (e.g., play skills, communication skills, self-care skills)? _____
7. other <u>(please specify)</u>: _____

Current Needs of Preschool-Aged Children

Part 3

Instructions: For each statement below, please choose the numerical rating corresponding to the descriptor that best reflects the extent to which that item is a need of yours and your family's at the present time. In choosing a number from 1 to 5 please think of the following descriptors:

never	*seldom*	*somewhat*	*usually*	*always*
1	*2*	*3*	*4*	*5*

Example

1. It is necessary for me to encourage my child with a disability to be as independent and competent as possible. 5

2. It is necessary for me to encourage my child without a disability to recognize and feel good about the positive things that he/she does 2

In the above examples, the parent indicated that he/she always has to encourage his/her child with a disability to be as independent and competent as possible. However, the parent seldom has to encourage his/her child without a disability to recognize and feel good about the positive things that he/she does.

Category 6: Characteristics of Your Child(ren) with Disabilities

Instructions: Listed below are some commonly expressed needs of preschool-aged children with disabilities, as perceived by parents. If you have more than one child with a disability, please feel free to provide additional information regarding each child in the space provided under each question.

Please think about your preschool-aged child(ren) with a disability. To what extent do you need to:

1. encourage my child(ren) to be as independent as possible with personal-care and self-help skills? _____

Comments

_____
_____
_____
_____

2. help my child(ren) to recognize and feel good about the positive things that he/she does? _____

Comments

_____
_____
_____
_____

never	*seldom*	*somewhat*	*usually*	*always*
1	*2*	*3*	*4*	*5*

3. help my child(ren) understand that there are expectations for appropriate behavior and consequences for unacceptable behaviors? _____

Comments

4. encourage my child(ren) to play with his/her siblings without disabilities? _____

Comments

5. help my children to play cooperatively with each other? _____

Comments

6. encourage my child(ren) to play with other children (e.g., peers from school, cousins)? _____

Comments

7. encourage my child(ren) to participate in the community (e.g., parks & recreational programs)? _____

Comments

never	*seldom*	*somewhat*	*usually*	*always*
1	*2*	*3*	*4*	*5*

Category 7: Characteristics of your Preschool-Aged Siblings of Children with Disabilities

Instructions: Listed below are some commonly expressed needs of preschool-aged siblings without disabilities, as perceived by the parents. If you have more than one preschool-aged child without disabilities, please feel free to provide additional information regarding each child in the space provided under each question.

Please think about your preschool-aged child(ren) without a disability. To what extent to do you need to:

1. help my child(ren) recognize and feel good about the positive things that he/she does? _____

Comments

_____
_____
_____
_____

2. remind my child(ren) to let his/her sibling with a disability to do as many things as possible without assistance? _____

Comments

_____
_____
_____
_____

3. encourage my child(ren) to play with other children of his/her own age in the neighborhood? _____

Comments

_____
_____
_____
_____

4. encourage my child(ren) to play with his/her sibling(s) with a disability? _____

Comments

_____
_____
_____
_____

never	*seldom*	*somewhat*	*usually*	*always*
1	*2*	*3*	*4*	*5*

5. encourage my child(ren) to participate in community and/or recreational activities with children of his/her own age? _____

Comments

_____
_____
_____
_____

6. encourage my child(ren) to be responsible for some care of his/her sibling(s) with a disability? _____

Comments

_____
_____
_____
_____

7. encourage my child(ren) to talk about his/her concerns or fears about his/her sibling's disability _____

Comments

_____
_____
_____
_____

8. reassure my child(ren) that he/she isn't responsible for his/her sibling's disability? _____

Comments

_____
_____
_____
_____

9. reassure my child(ren) that he will not 'contract' his/her sibling's disability? _____

Comments

_____
_____
_____
_____

10. praise my child(ren) for the time he/she spends taking care of his/her sibling(s) with a disability? _____

Comments

_____
_____
_____

never	*seldom*	*somewhat*	*usually*	*always*
1	*2*	*3*	*4*	*5*

11. encourage my child(ren) to teach his/her sibling(s) how to do different tasks (e.g., dressing, eating, playing with a toy, etc.)? _____

Comments

_____
_____
_____
_____

12a. Are expectations for appropriate behavior the same for each child in the family?

Yes _____ No _____

12b. If you answered no, to what extent do you need to remind your child(ren) that expectations for his/her appropriate behavior are different from those of his/her sibling(s) with a disability?

Comments

_____
_____
_____
_____

Please feel free to add any additional comments that you feel may be helpful.

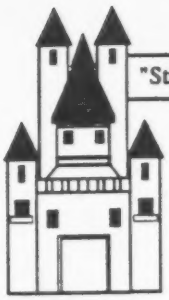
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

As mentioned in the consent form, the researcher is interested in conducting a follow-up telephone interview with interested parents to discuss general concerns of preschool-aged siblings of children with disabilities in more detail. The researcher requests that you place a check in the space provided if you are interested in participating in a follow-up telephone interview. If not, place a check in the space provided below.

_____ I give permission for the researcher to contact me once the questionnaires have been collected and summarized to discuss my answers and opinions. If so, please provide a phone number where you can be reached during the day or evening and a convenient time to call _____

_____

Thank you for your cooperation! Your input is greatly appreciated!



Waverley School

6825 - 89 Avenue, Edmonton, Alberta T6B 0N3 Telephone (403) 469 - 6682

June 16, 1992

Dear Parents:

A student from the University of Alberta, Darlene Tanchak, has asked us to assist her in her research project. She is interested in learning about families with children in the Early Education Program who have other preschool age children, as well. Because you fit the criteria I am sending you a questionnaire and a consent form. If you wish to participate in this study, please complete the attached questionnaire and consent and return them to Darlene.

Thank you for considering participating in this project. If you have any questions about the study, please phone me at 469-6682.

Sincerely,

Mary

Mary Holdgrafer, M.ED.
Curriculum Coordinator

MAYFIELD SCHOOL
ELEMENTARY AND EARLY EDUCATION
10950 - 159 Street, Edmonton, Alberta T5P 3C1
Phone 489-5100 Fax 448-0492

June 16, 1992

Dear Parents,

Darlene Tanchak, a graduate student from the University of Alberta, is conducting a study of the needs and concerns of preschool - aged children having siblings with disabilities. She is conducting this research to improve the following:

a) services to families of young children with disabilities and their preschool - aged siblings;
b) programs for training professionals to work with families.

She would like your opinions on the needs and concerns of your preschool child(ren) with and without disabilities. It would be very helpful if you would complete the enclosed consent form and survey by July 6, 1992 and return it in the self-addressed and stamped envelope.

This research has received ethical approval from the University of Alberta and Edmonton Public Schools. Your responses, along with those of other parents, will be compiled and used to help families with preschool - aged children having siblings with disabilities. Your responses will be treated in a confidential manner by the researcher.

If you have any questions, please feel free to contact me at 489-5100. Thank you in advance for your participation.

Sincerely,

Joan Rittman,
Curriculum Coordinator

JR/lb

L81

APPENDIX D

September 14, 1992

Dear Parents:

I am a graduate student from the University of Alberta and as a project for my thesis, I am conducting a study on the needs and concerns of preschool - aged children having siblings with disabilities. I am conducting this research to improve the following: (a) services to families of young children with disabilities and their preschool - aged siblings; and (b) programs for training professionals to work with families. I am very interested in your opinions on the needs and concerns of your preschool - aged child(ren) with and without disabilities.

This research has received ethical approval from the University of Alberta and Edmonton Public Schools. Families qualifying for the study were selected by the Early Education Coordinators. The Coordinators received the surveys from the researcher and sent them home with your children. The researcher didn't have access to the names of parents with children attending an Early Education Program at any time.

Your responses, along with those of other parents, will be compiled and used to help other families with preschool - aged children having siblings with disabilities. Please note that all of your responses will be treated in a confidential manner. As such, your name or the names of your family will not occur on any part of the research.

It would be very helpful if you would complete the enclosed consent form and 'Preschool Sibling Survey' by October 9, 1992 and return it in the self-addressed envelope. A total of 20 surveys have been completed and returned to the researcher so far.

If you completed a 'Preschool Sibling Survey' in June, 1992, I would like to thank you for your participation. Parents who indicated that they were interested in participating in the follow - up telephone interview will be contacted in October. If you know a family that qualifies for the survey and might be interested, please feel free to give them your package. If not, please return the survey in the self - addressed envelope.

If you have any questions, please feel free to contact me at 435 - 5127 or your Early Education Coordinator. Thank you in advance for your participation.

Sincerely, Darlene M. Tanchak

APPENDIX E

Follow-Up Telephone Interview

Hello, my name is Darlene Tanchak. I am a graduate student from the University of Alberta. ___weeks/months ago, you completed and returned the Preschool Sibling Survey. Also, I noted that you consented to participating in a follow-up telephone interview.

First, I would like to thank you again for completing the survey and consenting to the follow-up telephone interview. I really appreciated all of your input!

For this interview, I am interested in finding out more about the general needs and concerns preschool-aged siblings of children with disabilities. Would this be a convenient time to speak with you? If participant says no, ask for a convenient time to call back.

Follow-up Phone Call

Date: _____

Time: _____

Read Instructions:

Please think about your family and other families having preschool-aged children with and without disabilities that you may know personally. I am going to read eight statements to you. After each statement, please indicate whether you agree or disagree with the statement. Following each statement, I will then ask you to provide any comments, suggestions, and/or recommendations that you might have.

1. It is becoming more difficult to access local support groups which provide family support, information regarding respite care and financial assistance.

   Agree *Disagree* *Other*

   Comments

2. What would you suggest or recommend to parents who would like more information on accessing local support groups which provide family support, respite care, and financial assistance?

3. There is a need for increased parent-professional communication regarding the needs and concerns of preschool-aged siblings of children with disabilities.

   Agree *Disagree* *Other*

   Comments

4. If respondent agreed with statement 4, ask the following: In general, what type of professional would parents feel comfortable with when discussing issues concerning their preschoolers without disabilities?

5. Parents need to encourage and help their preschool-aged siblings of children with disabilities to play cooperatively

Agree *Disagree* *Other*

Comments

6. What would you suggest or recommend to parents who require assistance in helping their children to play cooperatively?

7. Parents need to remind their children that expectations for appropriate behavior are different from those of their brothers and sisters with disabilities.

Agree *Disagree* *Other*

Comments

8. What would you suggest or recommend to parents who require assistance with reminding their children that expectations for appropriate behavior are different from those of their siblings with disabilities?

9. Preschool-aged siblings of children with disabilities have more care-giving responsibilities than same-age peers without brothers and sisters with disabilities.

Agree *Disagree* *Other*

Comments

10. What would you suggest or recommend to parents who want to reduce the number of care-giving responsibilities that their preschoolers without disabilities currently have?

11. Generally speaking, children with disabilities require more time and attention from parents than their siblings without disabilities.

Agree *Disagree* *Other*

Comments

12. What would you suggest or recommend to parents who want to spend more quality time with each child, but find it difficult to do when much of their time is needed with their children with disabilities?

13. Generally speaking, parents who openly communicate with the family about their child's disability, are more likely to influence positive adjustment by the siblings without disabilities.

Agree *Disagree* *Other*

Comments

14. What would you suggest or recommend to parents who find it difficult to openly communicate with their child(ren) without disabilities about their brother or sister with a disability?

15. The severity of the disability influences a sibling's adjustment to the arrival of a brother or sisters with a disability.

Agree *Disagree* *Other*

Comments

16. What would you suggest or recommend to parents who want to ease their child's adjustment to the arrival of a brother or sister with a disability?

17. Do you have any additional comments, suggestions, and/or recommendations that you would like to make specific to the Preschool Sibling Survey, or to the statements given during this interview?

Thank you very much for taking time to discuss your opinions, suggestions, and recommendations with me. As you might remember in the consent form, each E. E. P. will receive a copy of the results as well as a list of fiction and non-fiction books about families having children with disabilities. I hope these references will be useful to you. If you wish to discuss the results of the study, please feel free to contact me at 464-5809.

APPENDIX F

Summary of Group Responses to Preschool Sibling Survey

Category 1 - Information

Item Description	no need (%)	low (%)	moderate (%)	high (%)	very high (%)	no response (%)
1. Books and materials	6	41	12	30	6	6
2. Managing Behaviors	6	18	30	18	24	6
3. Playing and talking with children	24	18	24	18	12	6
4. Growth and development of children	30	24	24	18	0	6
5. Access financial services	24	18	24	18	12	6
6. Community resources and services for siblings	18	18	24	18	18	6
7. Community programs and services for families	18	41	12	12	12	6
8. Access respite care	29	24	29	6	6	6
9. Access babysitting services	53	12	12	6	12	6
10. General information about siblings	12	12	35	29	6	6
11. Future school placements	0	12	0	24	65	0
12. Medical condition, equipment and supplies	35	24	24	6	6	6
13. Access specialized therapy therapy services	0	24	24	18	35	0
14. Parent support groups	35	24	24	6	6	6

Category 2 - Professional Support

Item Description	no need (%)	low (%)	moderate (%)	high (%)	very high (%)	no response (%)
1. Provision of respite care services	18	29	18	12	12	12
2. Provision of babysitting services	24	24	18	12	18	6
3. Availability of parent support groups	30	24	30	6	6	6

Item Description	no need	low	moderate	high	very high	no response
	(%)	(%)	(%)	(%)	(%)	(%)
4. Availability of professional services	0	0	35	35	24	6
5. Education programs for child with disabilities	24	0	18	0	47	12
6. Education program for child without disabilities	41	0	24	0	24	12
7. Counseling for the family	59	6	12	6	6	12
8. Availability of school workshops/sessions for parents	18	18	29	18	6	12
9. More contact with In-Home Consultants	29	41	18	0	6	6
10. More time to talk with teachers	12	24	53	6	0	6
11. More time to talk with parents	29	18	29	12	6	6

Category 3 - Community/Generic Support

Item Description	no need	low	moderate	high	very high	no response
	(%)	(%)	(%)	(%)	(%)	(%)
1. Availability of transportation services for child with disabilities	35	18	29	12	6	0
2. Availability of transportation services for child without disabilities	53	24	18	6	0	0
3. Contact with other parents	24	29	29	18	0	0
4. Availability of recreational programs for child with disabilities	0	24	24	18	30	6
5. Availability of recreational programs for child without disabilities	24	18	29	12	18	0
6. Assistance in locating a doctor	53	24	6	12	6	0
7. Meet and talk with parents	24	35	18	12	12	0
8. Meet with Minister, Priest, or Rabbi	82	6	6	0	6	0

Category 4 - Family Support

Item Description	no need (%)	low (%)	moderate (%)	high (%)	very high (%)	no response (%)
1. More quality time with child without disabilities	24	6	29	18	24	0
2. More quality time with child with disabilities	18	6	24	18	35	0
3. More quality time with spouse	12	6	18	24	29	12
4. Time to discuss problems with spouse	12	12	29	18	18	12
5. More support from spouse during difficult times	29	24	6	12	18	12
6. Emotional support from spouse during difficult times	24	24	24	18	12	0
7. Emotional support from friends	29	18	29	6	18	0
8. Help family discuss problems and support	6	12	18	24	41	0

Category 5 - Strategies

Item Description	no need (%)	low (%)	moderate (%)	high (%)	very high (%)	no response (%)
1. Reduce and cope with stress and anxiety	0	6	24	35	35	0
2. Communicate with family, school staff, and medical professionals	0	18	53	12	18	0
3. Manage behavior of child without disabilities	24	12	35	12	18	0
4. Manage behavior of child with disabilities	6	12	29	18	35	0
5. Advocate for child with disabilities	18	6	35	6	29	6
6. Teach child with disabilities	6	12	18	35	29	0

Category 6 - Characteristics of Your Child(ren) with Disabilities

Item Description	never	seldom	somewhat	usually	always	no response
	(%)	(%)	(%)	(%)	(%)	(%)
1. Encourage independence with self-help skills	0	0	24	18	53	6
2. Help child to recognize and feel good about him/ herself	0	6	18	18	59	0
3. Expectations for appropriate behavior	0	0	12	35	47	6
4. Play with siblings without disabilities	12	24	18	18	18	12
5. Play cooperative with each other	12	12	35	18	18	6
6. Encourage play with other children	12	24	24	12	24	6
7. Encourage participation in community activities	24	29	24	18	6	0

Category 7 - Characteristics of Your Child(ren) without Disabilities

Item Description	never	seldom	somewhat	usually	always	no response
	(%)	(%)	(%)	(%)	(%)	(%)
1. Help child to recognize and feel good about him/ herself	0	12	6	24	59	0
2. Remind child to allow sibling to do things for him/ herself	0	24	24	24	24	6
3. Play with children in the neighborhood	29	18	24	12	12	6
4. Encourage play with sibling(s)	24	29	12	6	24	6
5. Encourage child to participate in community activities	29	18	41	0	0	12
6. Encourage child to assume some care	18	24	29	12	6	12
7. Encourage open communication	24	18	24	0	18	18
8. Reassure child is not responsible for the disability	47	6	6	0	24	18

Item Description	never	seldom	somewhat	usually	always	no response
	(%)	(%)	(%)	(%)	(%)	(%)
9. Reassure child will not contract the disability	53	18	0	0	6	24
10. Praise child for taking care of the sibling	12	18	12	0	35	24

APPENDIX G

Reading Materials for Families of Children with Disabilities

Books for Siblings of Children with Hearing Impairments

Claire and Emma by Diana Peter and John Day. Adam and Charles Black, 1976.

I Have a Sister, My Sister's Deaf by Jeanne Peterson.

A Button in the Ear by Ada Litchfield. Albert Whitman and Company, 1976.

Is It Catching? A Book for Children with Hearing Impaired Sisters or Brothers by Ellen Hall.

A Hug Just Isn't Enough by Carol Ferris.

My Sister's Silent World by Catherine Arthur.

Lisa and Her Soundless World by E. S. Levine. Human Sciences Press, 1974.

A Dance to Still Music by B. Corcoran.

Anna's Silent World by B. Wolfe.

Silent Dancer by Bruce Hlibok. Messner, 1981.

Apple is my Sign by Mary Riskind. Houghton Mifflin, 1982.

The Swing by Emily Hanlon, Bradbury. 1979; Dell, 1981.

A Show of Hands by Mary Beth Sullivan and Linda Bourke. Addison-Wesley, 1980.

Books for Siblings of Children with Emotional and/or Behavioral Challenges

Walkie-talkie by Phyllis Green. Addison-Wesley, 1978.

Mad Martin by Patricia Windsor. Harper and Row, 1976.

Books for Siblings of Children with Epilepsy

Epilepsy by Alvin and Virginia Silverstein. J. B. Lippincott Junior Books, 1975.

A handful of Stars by Barbara Girion. Charles Scribner's Sons, 1981.

What if they knew? by Patricia Hermes. Harcourtbrace Jovanovich, 1980.

Books for Siblings of Children with Speech Impairments

Trouble with Explosives by Sally Kelley. Bradbury, 1976.

I can't talk like you by Althea. Dinosaur Publications, 1982.

Books for Siblings of Children with Physical Disabilities

Ginny edited by Alan Brightman and Kim Storey. Scholastic's Feeling Free, 1978.

Hollis edited by Alan Brightman and Kim Storey. Scholastic's Feeling Free, 1978.

Hackett McGee by Charles Grealish and Mary Jane Grealish. Scholastic's Feeling Free, 1978.

Alesia by Eloise Greenfield and Alesia Revis. Philomel, 1981.

Wheelchair Champions by Harriet May Savitz. Harper and Row, 1978.

Sports for the Handicapped by Anne Allen. Walker, 1981.

Run, Don't Walk by Harriet May Savitz. Accent Special Publications, 1979.

Mister O'Brien by Prudence Andrew. Heinemann, 1972.

Mark's Wheelchair Adventures by Camilla Jessell. Methuen, 1975.

Janet at School by Paul White. Adam and Charles Black, 1978.

Books for Siblings of Children with Learning Disabilities

Keep Stompin' till the Music Stops by Stella Pevsner. Seabury, 1977.

But I'm ready to go by Louise Albert. Bradbury, 1976.

Kelly's Creek by Doris Buchanan Smith. Harper and Row, 1975.

My Brother Barry by Bill Gillham. Andre Deutsch, 1981.

'I Own the Race Course!' by Patricia Wrightson. Hutchinson, 1972.

Books for Siblings of Children with Mental Retardation

Welcome Home, Jellybean by Marlene Shyer. Granada, 1981.

The Alfred Summer by Jan Slepian. Macmillan, 1980.

He's my Brother by Joe Lasker. Albert Whitman and Company, 1974.

My Brother Steven is Retarded by Harriet Sobol. Macmillan, 1977.

A Look at Mental Retardation by Rebecca Anders. Lerner Publications, Minneapolis, Minnesota, 1976.

Don't Take Teddy by Babbis Friis-Baastad. Charles Scribner's Sons, 1967.

The Summer of the Swans by Betsy Byars. Viking Press, 1970.

A Racecourse for Andy by Patricia Wrightson. Harcourt, Brace, and World, 1968.

Take Wing by Jean Little. Little, Brown, and Company, 1968.

Mary Fran and Mo by Maureen Lynch. St. Martin's Press, 1979.

My Sister by Karen Hirsch. Carol Rhoda Books, Minneapolis, 1977.

A Special Kind of Sister by Lucia Smith. Holt, Rinehart, and Winston, 1977.

She's my Sister by Jane Claypool Miner. Pitman Learning, Inc., Belmont, California, 1982.

The BlueRose by G. Klein. Lawrence Hall and Company, 1974.

A Place for Everyone by Tana Reiff. Fearon-Pitman, 1979.

Sticks and Stones by Lynn Hall. Follett, 1972.

Books for Siblings of Children with Autism

The Devil Hole by Eleanor Spence. lothrop, Lee and Shepard, 1977.

The October Child by Eleanor Spence. Oxford University Press, 1976.

Please Don't Say Hello by Phyllis Gold. Human Sciences Press, 1976.

Books for Children with Visual Impairments

Belonging by Deborah Kent. Ace Books, 1979.

Listen for the Singing by Jean Little. E. P. Dutton, 1977.

Being Blind by Rebecca Marcus. Hastings House, 1981.

Tom and Bear by Richard McPhee. Thomas Y. Crowell, 1981.

Laurie by Diane Greig and Aan Brightman. Scholastic's Feeling Free, 1978.

Connie's New Eyes by Bernard Wolf. Harper and Row, 1976.

SallyCan't See by Palle Petersen. John Day Company, 1977.

Spectacles by Ellen Raskin. Connecticut Printers, Inc., 1968.

The Seeing Summer by J. Eyerly. J. B. Lippincott, 1981.

Siblings of Children with Cerebral Palsy

Let the Balloon Go by Ivan Southall. Methuen, 1968.

Mine for Keeps by Jean Little. Little, Brown and Company, 1962.

helps himself by J.. Albert Whitman and Company, 1975.

Books for Families of Children with Disabilities:

A Difference in the Family by Helen Featherstone.

Families of Hearing Impaired Children by Albert T. Murphy.

The Silent Garden: Understanding the Hearing Impaired Child by Paul Ogden and Susanne Lipset.

Family to Family, published by Alexander Graham Bell Association for the Deaf, 1980

For Parents of Deaf Children by Doris W. Naiman and Jerome D. Schein.

Breaking Silence--A Family Grows with Deafness by Ferne Glick and Donald Pellma.

Deafness and Child Development by Kathryn Meadow.

Raising Your Hearing-Impaired Child: A Guideline for Parents by Shirley McArthur.

Friends by Melva Jackson Edrington. Instructional Development Corp., P. O. Box 361, Monmouth, Oregon, 97361, 1978.

Like me by Alan Brightman. Little, Brown and Company, 1976.

What if you couldn't ...? A Book About Special Needs by Janet Kamlen. Charles Scribner's sons, 1979.

Who will Take Care of Me? by Patricia Hermes. Harcourt Brace Jovanovich, 1983.

The Raft by Alison Morgan. Abelard-Schuman, 1974.

What do you do when your wheelchair gets a flat tire? edited by D. Biklen and M. Sokoloff. Scholastic Book Services, 1978.

Like it is: Facts and feelings about handicaps from kids who know by Barbara Adams. Walker, 1979.

Winners: Eight special young people by Dorothy Siegel. Messner, 1978.

Feeling free by Mary Beth Sullivan, Alan Brightman, and Joseph Blatt. Addison-Wesley, 1979.

About handicaps: An open family book for parents and children together by Sara Bonnett Stein. Walker, 1984.

Health, Illness and Disability: A guide to books for children and young adults by Pat Azarnoff. R. R. Bowker, 1983.

Siblings Without Rivalry by Adele Faber and Elaine Mazlish. Avon Books, 1987.

The Parent-Child Connection by Arnold Rincover. Random House, 1988.

How to Talk so Kids will Listen & Listen so Kids will Talk by Adele faber and Elaine Mazlish. avon Books, 1980.

Win the Whining War and other Skirmishes by Cynthia Whitham. Perspective Publishing, 1991.

Brothers and Sisters - A Special Part of Exceptional Families by Thomas H. Powell and Peggy Ahrenhold Ogle.

Brothers, Sisters, and Special Needs by Debra J. Lobato.

Leader's Companion Packet - for Brothers, Sisters, and Special Needs by Debra lobato.

A Difference in the Family: Life with a Disabled Child by Heather Featherstone.

Families of handicapped children: Needs and supports across the life span by R. Fewell and P. Vadasy.

Hope for the Families: New Directions for Parents of Persons with Retardation or other Disabilities by Robert Perske.

The Disabled Child and the Family by M. Schleifer and S. Klein.

The Family with a Handicapped Child by M. Seligman.

After the Tears: Parents Talk about Raising a Child with Disabilities by R. Simons.

Health, Illness and Families: A Life-span Perspective by D. Turk and R. Kerns.

Parents Speak Out: Views from the Other Side of the Two-Way Mirror by A. Turnbull and H. Turnbull.

Barry's Sister by Lois Metzger. Macmillan Publishing Company, 1992.

All by Self by Ron Taylor. Lights On Books and Video Tapes, 1990.

The Sibling Information Network Newsletter is published on a quarterly basis. The Newsletter publishes manuscripts, announcements and information for and about siblings of persons with disabilities as well as other issues related to families of persons with disabilities. This newsletter also has a SibPage with activities, letters from other siblings, a problem and answer column for siblings.

Contact: Lisa Papanikou
Coordinator
Sibling Information Network
CUAP
991 Main Street
East Hartford, CT 06108
(203) 282-7050

Videos for Families of Children with and without Disabilities

Time together: Learning to play with youg children (1989)

Educational Productions
7412SW Beaverton
Hillsdale Highway
Suite 210
Portland, Oregon 97225
(503) 292-9234

What about me? Brothers and sisters of children with disabilities (1990)

Educational Productions
7412 SW Beaverton Hillsdale Highway
Suite 210
Portland, Oregon 97225
(503) 292-9234

Pedro (1988)

Resources in Special
Education
650 Howe Avenue
Suite 300
Sacramento, CA 95825
(916) 641-5925

Someday's child: A focus on special needs children and their families (1989)

Educational Productions
7412 SW Beaverton Hillsdale Highway
Suite 210
Portland, Oregon 97225
(503) 292-9234